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Medicare Alzheimer's Disease Demonstration Evaluation

Report to Congress
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Medicare Alzheimer's Disease Demonstration Evaluation
Interim Report To Congress
Summary

The attached Interim Report to Congress on the Medicare Alzheimer's Disease Demonstration Evaluation was prepared by the Institute for Health and Aging, University of California, San Francisco under HCFA contract 500-89-0069. It presents information regarding the eight organizations which conducted the demonstration and the services they provided to participating Medicare beneficiaries and their caregivers.

The Medicare Alzheimer's Disease Demonstration was authorized by a provision of the 1986 Omnibus Budget Reconciliation Act. The purpose of the project was to determine the effectiveness, cost, and impact on health status and functioning of providing in-home and community-based services to beneficiaries with Alzheimer's disease or a related disorder.

This Interim Report to Congress chronicles the implementation of the project and the early operational experience of each of the demonstration sites. It identifies the program characteristics of the individual sites, such as sponsorship, catchment area, case management activities, community resources, and staffing configurations. The University of California, San Francisco's report provides descriptive summaries of these organizational dimensions to facilitate cross-site comparisons. It also includes preliminary findings of the project's evaluation.

Chapter 1 of the report begins with an overview of the epidemiology of dementia and a summary of the research history of Alzheimer's disease. It provides an extensive literature review on the research which has been conducted to learn more about the cost and prevalence of Alzheimer's disease and the service use patterns of the cognitively impaired. For example, data suggest that persons with dementia use a disproportionate amount of medically oriented skilled nursing care. The utilization of health care and social services by the elderly and the cost of these services are discussed. In addition, this chapter examines the impacts of caring for someone with cognitive impairment and the utilization of formal services by these caregivers.

The demonstration's objectives and program design are presented in Chapter 2. Although it is estimated that seven million Americans have dementia, relatively little is known about the health care needs of these individuals. This project was designed to assess the effect of providing home care services to beneficiaries with Alzheimer's disease using a case managed system approach and expanded Medicare funding.

Two models of care were studied under the demonstration. Both Model A and Model B included case management and a comprehensive package of home and community-based services not presently covered under Medicare such as adult day care, homemaker/personal care services, companion services, and counseling. The intensity of the case management provided to beneficiaries and their caregivers and the amount of reimbursement available for the provision of services differentiated the models.

An experimental design was used to evaluate the project. This type of design was adopted to help insure that any differences observed between the randomly assigned treatment and control group members can be attributed to the interventions being tested. The eligibility criteria defined for beneficiary enrollment in the demonstration are described.

Chapter 3 of the report identifies the major research questions and hypothesized impacts of the project. Some of the questions to be addressed by the evaluation are: 1) how do the various services provided under the demonstration affect the functional status of Medicare beneficiaries with Alzheimer's disease, 2) what effect do project services have on the caregivers of these beneficiaries, 3) does the provision of an expanded package of services delay or prevent institutionalization, and 4) what are the effects of alternative reimbursement on service utilization and the distribution of the burden of cost for public and private payers. The two models are anticipated to have similar impacts on beneficiaries and their caregivers but the magnitude of these outcomes are expected to vary because of the differences in the case management protocols and the amount of monthly reimbursement available for demonstration services.

In Chapter 4 the project's evaluation design, data collection procedures and instruments, study sample, and sample attrition are described. Six sources of data were used to measure the impacts of the demonstration. Information was collected from both primary and secondary sources. During the initial interview a Mini-Mental Status Examination was administered to assess cognitive functioning. After this interview the beneficiary was randomized into either the treatment or control group. An experimental design was used to assure observed and unobserved comparability between these two groups at enrollment. The absence of systematic differences at baseline provides greater confidence in interpreting later systematic differences as treatment effects. Baseline data were used for clinical and research purposes.

The demonstration's implementation and operational issues are discussed in Chapter 5. Policy and procedure were developed in the context of the evaluation design to ensure uniformity and consistency across all of the participating organizations. Technical assistance was provided to the sites by the University of California, San Francisco to facilitate the project's implementation and evaluation. This chapter reviews process issues such as demonstration eligibility, case management protocols, attrition replacement, and minimum data requirements.

Chapter 6 provides a description of the eight organizations which conducted the project including their history, sponsorship, and structure. Each site's service environment and its local long term care service system are also discussed. The availability, accessibility, and quality of care of community-based services are evaluated to determine their impact on the demonstration.

This chapter examines the difficulties encountered in reaching the project's enrollment goals. Locating and recruiting eligible beneficiaries presented different challenges to each of the demonstration sites. The reasons for these difficulties and the outreach strategies implemented to counteract them are described. The case management activities and the service utilization patterns at the participating organizations are identified.

The project's preliminary findings including baseline characteristics of the study sample and analyses of beneficiary and caregiver outcomes are summarized in the final chapter of the Interim Report to Congress. During the project the sites enrolled more than 8,000 Medicare beneficiaries. Initially, the demonstration experienced an unexpectedly high attrition rate. The major reasons for disenrollment were death or nursing home placement. Since attrition was greater than originally anticipated, the demonstration's caseload build-up period was extended to give the sites more time to recruit other Medicare beneficiaries.

While the eligibility criteria for the demonstration identified a broad range of irreversible cognitive disorders, preliminary findings reveal that most of the beneficiaries had Alzheimer's disease (66-75 percent). Other common diagnoses included vascular dementia and dementia resulting from degenerative conditions, such as Parkinson's, Pick's, and Huntington's disease. The Blessed Roth Dementia Rating Scale and the Mini-Mental Status Examination were used to measure cognitive functioning. Scores on both of these instruments indicated that the typical demonstration participant had mild to moderate dementia.

The level of beneficiary functional impairment was high, averaging more than five limitations in 10 activities of daily living (e.g., walking, transferring, grooming, bathing, toileting, and eating) and more than seven limitations in eight instrumental activities of daily living (e.g., meal preparation, shopping, money management, and housework). About 60 percent of the caregivers reported that the beneficiaries required constant supervision. The majority of the beneficiaries who received services under the demonstration were female (60 percent) and white (88 percent). The average age of this group was 79.

Spouses and female children predominated as caregivers for the participating beneficiaries. During the first 6 months after their enrollment into the project, about four to six percent of the caregivers changed. This substitution pattern was consistent across both treatment and control groups. More than half of the caregivers were married and almost 50 percent were the spouse of the beneficiary. However, a substantial number of caregivers were widowed, divorced, or separated.

The caregivers in this demonstration were only a few years younger than the beneficiaries. The average age of this group was 74. Many had their own functional limitations and had difficulty performing basic tasks like housework, shopping, laundry, and meal preparation. About 25 percent of the caregivers considered their health as fair or poor.

This Interim Report to Congress also profiles the utilization patterns of demonstration services. A wide variety of home and community-based services were available under the project. Case management was the primary intervention. Some of the other services were adult day care, personal care services, homemaker chore services, companion services, and family counseling.

According to preliminary findings, there were large differences in the use of adult day care by model and by group. Forty-two percent of the Model B treatment group members utilized this service compared to 25 percent of the Model A treatment group. Personal care services were used by less than half of the participating beneficiaries. In both models, approximately one-third of the treatment group members used homemaker chore services compared to about one-fourth of the control group. Companions were used by only one-fifth of the beneficiaries in the control group with utilization rates 50 to 100 percent higher for the treatment group. A comprehensive analysis of the service use of both the beneficiaries and their caregivers is included in the report.

Case management, the most important component of the demonstration, was used by 95 percent of all demonstration participants. Those individuals who did not receive this service indicated in a survey that it was not needed. Satisfaction with case management was relatively high, especially among beneficiaries and caregivers at the Model B sites. The project's preliminary findings are provided in narrative or tabular format.

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MEDICARE ALZHEIMER'S DISEASE DEMONSTRATION EVALUATION

Interim Report to Congress

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EXECUTIVE SUMMARY

Limitations in Medicare coverage of long term care for people with chronic dementing disorders, excessive variation in long term care services among the state Medicaid or Medicaid waiver programs, and an absence of knowledge of the health care service needs of people with Alzheimer's disease are three of the problems that prompted Congress to establish the Medicare Alzheimer's Disease Demonstration. The demonstration evaluation assesses (1) the effectiveness of this program in increasing access to an expanded range of Medicare-funded community-based long term care services; and (2) the consequences of this access for demented persons and their caregivers.

The Medicare Alzheimer's Disease Demonstration was implemented by the Health Care Financing Administration (HCFA) in 1989 in response to section 9342 of the Omnibus Budget Reconciliation Act (OBRA) of 1986. In September 1989, HCFA awarded contract No. 500-89-0069 to the University of California at San Francisco (UCSF) to provide training and technical assistance to the demonstration project sites and to evaluate the demonstration.

The original legislation in section 9342 of OBRA-86 specified that the project was to operate for 3 years. In response to this statutory requirement, the demonstration was scheduled to operate from May 1989 to May 1992. After a 6-month developmental period beginning in May 1989, the eight participating project sites began enrollment of clients in December 1989. The sites were scheduled to halt caseload build-up on December 31, 1990. The demonstration's goal was to enroll approximately 1,200 treatment group clients and 1,200 control group members under each model (i.e., a total of 4,800 individuals in the evaluation sample). The project sites were scheduled to operate at full caseload for one year and then begin a 5-month phase-down period in January 1992, with the demonstration ending in May 1992. This schedule would have permitted the evaluation contractor to track all clients for at least 12 months (i.e., the evaluator would conduct follow-up interviews with each client's family caregiver to measure the client/family status at two points in time--6 and 12 months after the client entered the demonstration).

Section 4164(a)(2) of OBRA-90 required that the demonstration be extended by one year (i.e., through May 1993). This congressional extension of the demonstration was motivated primarily by two concerns:

- An interest in lengthening the case management time period and collecting more longitudinal data in order to study whether the hypothesized benefits of the demonstration intervention (e.g., reductions in family caregiver stress/burden levels and in nursing home admissions) change over time as Alzheimer's patients' health status deteriorates over a period of years.

- Difficulty in achieving target sample sizes. This was due to a higher-than-expected rate of client attrition--approximately 28 percent annually--primarily because of institutionalization and death.

In response to this congressional mandate, HCFA extended the sites' caseload build-up period through October 1991 and the overall demonstration through May 1993. The sites under the revised schedule entered the "full caseload" operational period with a total caseload of approximately 3,000 treatment group clients on November 1. An equal number of clients were assigned to a control group. Because of the high attrition rates, the attainment of this caseload required that the sites enroll a total of 7,000 individuals over the 22-month period between December 1989 and October 1991. The project was extended for a second time by section 13552 of OBRA-93. This extension provided another opportunity to enhance the demonstration's longtudinal data.

POLICY ISSUES AND THE DEMONSTRATION

Alzheimer's disease is a progressive dementia primarily occurring in the later years of the life span, but it may appear as early as age 40. Persons with the disease are characterized by disorientation as to time, place, and person; deterioration of personality; and physical incapacitation. Alzheimer's disease is increasingly being recognized as a disease which places substantial financial burdens on the afflicted patient, his/her family, and the community. The onset of the disease is usually slow and gradual. Over time, the disease follows a deteriorating course. Patients who originally may have managed to perform routine household chores generally have problems with cognition and functional activities of daily living. Almost inevitably, this cognitive, functional, and behavioral deterioration culminates in the need for institutionalization, often for a period of several years.

While the health care delivery system is able to meet some of the needs of Alzheimer's disease patients for medical care, a large share of the burden in caring for such patients falls on relatives and friends. Hay and Ernst (1987) have estimated that the overall cost of Alzheimer's disease for all patients diagnosed in 1983 was between $27.9 billion and $31.2 billion.

In addition to these costs, there is growing evidence that providing care for persons with Alzheimer's disease can exact a psychological and physical toll on caregivers. Reductions in the health status of caregivers have been widely described (Sainsbury and Alencon, 1970; Archibald, 1982; Farkas, 1980; Barnes et al., 1981; Haley et al., 1987; Moriz, 1987) as have changes in mental health status, especially related to depression (Eagles 1987; Gilhooly, 1984; Moritz et al., 1989). It has been estimated that for every person residing in a nursing home, as many as two to three individuals living in the community receive care primarily from informal sources (HCFA, 1981).

The majority of caregivers of the elderly reported adjusted family incomes in the low to middle range (Stone and Cafferata, 1986) and research indicates that most services used by these people have to be privately purchased (U.S. General Accounting Office, 1977; Doty, 1985). Even for Medicaid eligible households, coverage for care is usually available only when a family has decided to institutionalize the patient. Regardless of income, persons with Alzheimer's disease and related disorders and their caregivers commonly experienced: (1) a lack of services that are targeted specifically to meet the needs of demented persons; and (2) a lack of reimbursement for health and social services for people with Alzheimer's disease. While many community-based long term care services are being developed throughout the country, often these are not appropriate for, or do not accept, persons with Alzheimer's disease.

DEMONSTRATION GOALS AND PROGRAM DESIGN

The Medicare Alzheimer's Disease Demonstration is designed for persons diagnosed with an irreversible dementing disorder who have an unmet need and are able to benefit from case management, financial support for services, and caregiver support. Eligible applicants must be enrolled in both Parts A and B of the Medicare program and must reside in the demonstration site's catchment area. Applicants who meet these criteria and who reside in a nursing home or hospital will be eligible to participate in the demonstration if they are discharged from the institution within one month of their application. Most of the data collected under the demonstration are obtained from the patient's primary informal caregiver, however participants were not required to have a source of informal assistance.

There are four basic goals of the demonstration: (1) ensuring the development of an effective network of community-based services that address the medical, mental health, and social support needs of persons with Alzheimer's disease and related disorders and their caregivers; (2) providing education and support services to caregivers to minimize stress associated with caregiving and to enhance caregiving skills; (3) creating opportunities for demented persons to be cared for in preferred, protective home-like environments and supporting the use of the most appropriate level of care whether in institutional or community settings and; (4) ensuring that the services provided are cost-effective and that the costs of care are equitably distributed. In addition to its work with clients and caregivers, the demonstration provides training for formal service providers to insure that workers are familiar with the special care needs of patients with Alzheimer's disease and related disorders.

Case management is the centerpiece of the demonstration. Case management assists the caregiver and patient in determining a service mix that best meets specific needs. It also helps assure that the services delivered are of sufficient quality. In-home and community-based out-of-home services are reimbursed under the demonstration.

Two basic case management models are being tested under the demonstration. These vary along two dimensions: the case manager-to-client ratio and the level of the allowable per-month expenditure for each client. A comparison of the basic characteristics of the two models is outlined below:

Model A *Low-Expenditure Cap*	**Model B** *High-Expenditure Cap Model*
1:100 case manager-to-client ratio	1:30 case manager-to-client ratio
Provides in-home services including homemaker/chore, personal care, home health, skilled nursing, as well as other services	Same
Provides medical, social, or Alzheimer's-specific adult day care	Same
Other community services	Same
Incorporates an overall "low" cap on per patient expenditures per month	Incorporates an overall "high" cap on per patient expenditures per month

These models were recommended by Mathematica Policy Research, Inc. (MPR) and approved by HCFA. Both models allow the provision of the same range of services. The differences in case management intensity and service expenditure caps allow a test of models at different funding levels. Demonstration sites are reimbursed for case management at cost, 80 percent for direct services, and 100 percent for direct services if the demonstration participant is also a Medicaid recipient. Except for Medicaid participants, patients and families pay for the remaining 20 percent of service costs. The cost-sharing approach is expected to provide patients and/or families with an incentive for cost consciousness.

The monthly cap amounts were adjusted for geographical cost variations and ranged initially from approximately $300 per month under Model A to about $500 under Model B.

Case managers are instructed under the demonstration guidelines to use public (e.g., Medicaid, Title XX, Title III) or private (e.g., United Way, Catholic Social Services, Jewish Federation) sources of funding for community health and social services prior to the use of demonstration-supported services. This is consistent with other forms of case management (e.g., channeling). Demonstration services could, however, be used to replace or supplement health or social services that clients or their family members pay for out of pocket.

The services covered under the demonstration include the following:

- adult day care
- skilled nursing
- rehabilitation nursing
- therapies (i.e., speech, occupational, physical)
- home health aide
- homemaker/personal care
- housekeeping
- general chore (i.e., heavy cleaning)
- home repairs and maintenance
- companion (i.e., friendly visiting, incidental shopping and errands, telephone reassurance)
- companion for education and training (so caregiver can leave home to participate in education/training sessions)
- home delivered meals
- non-emergency transportation for client
- adaptive and assistive equipment
- medical supplies
- durable medical equipment
- consumable care goods
- mental health treatment
- caregiver education and training
- family counseling
- caregiver transportation to support groups
- case management
- medical assessment

Eight demonstration sites have been funded. These sites began enrolling members in December 1989. The sites are located in different geographical regions of the United States:

Model A Sites

Monroe County Long Term Care Program,Inc.
Rochester, New York

Carle Clinic Association
Urbana, Illinois

Northeast Community Mental
Health Center
Memphis, Tennessee

Good Samaritan Hospital and
Medical Center
Portland, Oregon

Model B Sites

Cincinnati Area Senior Services, Inc.
Cincinnati, Ohio

Wood County Senior Citizens Association
Parkersburg, West Virginia

Amherst H. Wilder Foundation
Minneapolis, Minnesota

Miami Jewish Home and Hospital
for the Aged
Miami, Florida

RESEARCH QUESTIONS AND HYPOTHESIZED IMPACTS OF THE DEMONSTRATION

The demonstration is designed to address the following major questions:

- What factors are associated with the cost-effectiveness and impact on health status of providing expanded services to Alzheimer's disease and related disorders Medicare beneficiaries and their caregivers?
- In what ways do services provided under the demonstration affect the functional status of clients and the well-being of their family members?
- What are the effects of the provision of an expanded range of services, including caregiver support and counseling services, on caregiver burden?
- What is the impact of expanded training for formal and informal caregivers on the quality of care and client well-being?
- Do demonstration services delay or prevent the institutionalization of persons with Alzheimer's disease and related disorders?
- Do community outreach efforts mandated by the demonstration assist in the identification of previously unidentified persons with Alzheimer's disease and related disorders?
- What are the effects of alternative reimbursement caps on service utilization and on the distribution of the burden of cost for public and private payers?

THE EVALUATION DESIGN

An experimental study design is being used to test the impact of the Medicare Alzheimer's Disease Demonstration. A total of 6,040 clients were randomly assigned to the treatment (n = 3079) or control (n = 2961) group. These cases were selected between December 1989 and April 30, 1991. Each client is followed for up to 24 months. The final follow-up interviews will be completed on April 30, 1993. Each site continued to enroll clients from May 1, 1991, through November 30, 1992, in order to maintain a "steady-state" membership and a constant client-to-case manager ratio. The additional cases are not included in the evaluation results.

Six sources of data are used to measure the impacts of the Medicare Alzheimer's Disease Demonstration. The data sources include:

- Family application and physician forms for each applicant
- Baseline intake interview for all treatment and control members and their primary caregivers
- A 6, 12, 18 and 24-month follow-up interview with the caregivers of members of the treatment and control groups
- Medicare claims data to obtain information on service utilization and expenditures for the treatment and control groups
- Claims records submitted to HCFA from the sites to obtain information on the utilization and expenditures for services provided to the treatment group under the Medicare waivers
- Administrative reporting form to HCFA covering demonstration costs, site activities, staffing changes, etc.
- In-person discussions during the site visits with key individuals affiliated with the demonstration in order to obtain qualitative and quantitative assessments of program operations, start-up and implementation issues, and lessons learned from the demonstration.

Table 1 shows the number and proportion of clients randomized into the treatment and control groups. Within each site the clients were almost equally divided between the treatment and control groups with less than one percent difference in the proportion of clients in the experimental and control groups at each site. Overall, 51percent of the study sample was in the treatment group and 49 percent was in the control group. Model B sites had slightly more clients (53 percent of the 6,040 total sample members) than the Model A sites (47 percent).

TABLE 1

The Study Sample
Treatment & Control Groups, by Model, by Site

Group & Site	Treatment (n=1438)		Control (n=1392)		Total (n=2830)	
	N	%	N	%	N	%
Model A						
Illinois	370	25.7	364	26.1	734	25.9
New York	341	23.7	329	23.6	670	23.7
Oregon	367	25.5	357	25.6	724	25.6
Tennessee	360	25.0	342	24.7	702	24.8

Group & Site	Treatment (n=1641)		Control (n=1569)		Total (n=3210)	
	N	%	N	%	N	%
Model B						
Florida	469	28.5	454	28.9	923	28.8
Minnesota	551	33.6	511	32.6	1062	32.1
Ohio	394	24.0	366	23.3	760	23.7
West Virginia	227	13.8	238	15.2	465	14.5

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

Table 2 shows the number and proportion of sample members who attrited from the study between the baseline intake interview and the 6-month follow-up interview. Overall, sample attrition during the first 6 months of the study was slightly higher in Model B sites (11.2 percent) than in Model A sites (8 percent). For both Models the two primary reasons for attrition were death (5.5 percent in each Model) and permanent institutionalization (2.6 percent in Model B and 1.3 percent in Model A). Very small proportions of clients (less than two percent) attrited for any other reason (e.g. moved out of catchment area, lost to follow-up, refusal) during the first six months of the study.

Differences in attrition between treatment and control groups are not significant in either model. In both models, a slightly larger proportion of the treatment group members became permanently institutionalized during the first six months of the study, while a slightly larger proportion of the control group died.

TABLE 2

Sample Attrition at 6-Month Follow-up
Treatment & Control Groups, by Model

Group & Reason for Attrition	Treatment (n=1438)		Control (n=1392)		Total (n=2830)	
	N	%	N	%	N	%
Model A						
Institutionalized	24	1.7	14	1.0	38	1.3
Deceased	78	5.4	78	5.6	156	5.5
Moved out of area	16	1.1	11	0.8	27	0.9
Ineligible diagnosis	0		0		0	
Unable to locate	0		7	0.5	7	0.2
Refused	8	0.5	11	0.8	19	0.7
Other 1	4	0.3	2	0.1	6	0.2
TOTAL ATTRITION	130	9.0	123	8.8	253	8.9

Group & Reason for Attrition	Treatment (n=1641)		Control (n=1569)		Total (n=3210)	
	N	%	N	%	N	%
Model B						
Institutionalized	54	3.2	29	1.8	83	2.6
Deceased	71	4.3	108	6.9	179	5.5
Moved out of area	30	1.8	16	1.0	46	1.4
Ineligible diagnosis	0		0		0	
Unable to locate	1	0.1	2	0.1	3	0.1
Refused	17	1.0	21	1.3	38	1.1
Other 1	5	0.3	7	0.4	12	0.3
TOTAL ATTRITION	178	10.8	183	11.7	361	11.2

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

Description of the Demonstration Sites and Implementation Issues

The congressional mandate for the demonstration specifies that the evaluator provide a description of the demonstration sites and the implementation process. Sites visits were conducted at each of the eight sites during the months of June and July 1990. This time frame was selected so the sites would have enough time to "iron out the wrinkles" associated with the beginning of a major demonstration project but early enough so that implementation issues could be adequately documented.

Field instruments contained questions regarding: 1) the history and sponsorship of the demonstration; 2) the inter-organizational structure of community agencies leading the local demonstration implementation effort; 3) the local service environment of the demonstration site; 4) client outreach and enrollment activities; 5) case management services; and 6) demonstration service utilization patterns.

Questionnaires were developed for project directors, Alzheimer's Association representatives, service providers, local long-term care system experts, case managers/case aides, case management supervisors, host agency directors, and outreach-intake workers.

Additional data used for the site descriptions were derived from information reported by each site through monthly site reports. These reports provided information on client applications; active clients; case management activity; and accomplishments or difficulties encountered during the month.

A brief summary of key program characteristics for each site is presented by model to facilitate cross-site comparisons. Model A sites are summarized in Figure 1, and Model B sites are summarized in Figure 2.

Figure 1
Medicare Alzheimer's Disease Demonstration
Descriptive Summary of Model A Projects

Characteristic and Site	Illinois	New York	Oregon	Tennessee
Sponsorship	The MAP project is sponsored by the Carle Clinic of Urbana-Champaign, which is affiliated with the Carle Foundation.	The MAP project in Rochester is sponsored by: The Monroe Co. Long Term Care Program, Inc. (ACCESS), the Visiting Nurse Service, and the Monroe Co. Health Department.	The MAP project in Portland is sponsored by Good Samaritan Hospital and Medical Center.	The Alzheimer's Consortium sponsors the MAP project and is comprised of 17 health and social services providers.
Catchment Area	The demonstration operates out of five locations in East-Central Illinois. The catchment area covers 20 counties.	The catchment area includes all of Monroe County (including the city of Rochester and four rural areas) situated in upstate NY.	The catchment area encompasses all of Multnomah, Washington and Clackamas counties and portions of Columbia county.	The catchment area is the Memphis Delta Planning and Service Area in the southwest corner of Tennessee.
Program Staffing (April 30, 1991)	Total Staff: 15.3 FTE	Total Staff: 22.55 FTE	Total Staff: 15.9 FTE	Total Staff: 12.5 FTE
Service Environment	Community spokespersons rated the catchment area as having a fair long term care system.	Community spokespersons rated Monroe County as having a well developed long term care system.	Community spokespersons rated the catchment area as having a well developed long term care system.	Community spokespersons rated the urban county well developed. The three rural counties were classified as having a fair long term care system.
Demonstration Service Provision	Carle Clinic is the primary provider of services but also contracts with a total of 77 other service providers.	The Visiting Nurse Services and the Monroe County Health Department provide the majority of the services. ACCESS also contracts with with 53 other agencies.	Good Samaritan provided two services: companion services and caregiver education and training. All other services were contracted out to 22 service provider agencies.	Only 4 of the 17 consortium member agencies directly provided demonstration services. The majority of services were provided under contract with six other agencies.
Program Census (April 30, 1991)	284 Treatment Clients	263 Treatment Clients	303 Treatment Clients	301 Treatment Clients
Case Management Activities	Case managers spent the most time in: initial care planning/service arrangement (24%), initial assessment, service monitoring/ follow-up, and local travel (each 20%).	Case managers spent the most time in: service monitoring/ follow-up (28%) and initial assessment (19%).	Case managers spent the most time in: service monitoring/ follow-up (29%); administrative meetings (16%), and initial assessment (15%).	Case managers spent the most time in: service monitoring/ follow-up (41%) and initial assessment (18%).
Demonstration Service Utilization Trends (2nd Qtr. 1991)	Clients using only case management decreased over time, from a high of 37% during the 1st quarter 1991 to a low of 12% by June 1991.	Clients using only case management services increased over time, from 8% to 35%, and declined slightly to 32% by June 1991.	A relatively small proportion of clients were using only case management (10-20%) and declined to 11% by June 1991.	Clients using only case management services increased over time, from 24% to 41%, by June 1991.

Figure 2
Medicare Alzheimer's Disease Demonstration
Descriptive Summary of Model B Projects

Characteristic and Site	Florida	Minnesota	Ohio	West Virginia
Sponsorship	The Miami Jewish Home and Hospital for the Aged (MJHHA), a comprehensive geriatric facility, sponsors the MAP project.	The Minnesota sponsors include: Wilder Foundation (the lead agency), Metro-Minneapolis/St. Paul Chapter of the Alzheimer's Association, Ebenezer Society, and Miller-Dwan Medical Center.	The MAP sponsors include: Cincinnati Area Senior Services (the lead agency), Senior Citizens of Northern Kentucky, United Home Care, Greater Cincinnati Chapter of ADRDA, and Univ. of Cincinnati Medical Science Ctr.	Two agencies sponsor the MAP demonstration: the Wood County Senior Citizens Association, Parkersburg, and the Family Service - Upper Ohio Valley, Wheeling.
Catchment Area	The project serves two counties in the greater Miami area: Dade County and parts of southern Broward County.	The program serves three distinct areas: Greater St. Paul area (Ramsey, Dakota, and Washington Counties); Greater Minneapolis area (Hennepin County); Duluth and surrounding rural area (St. Louis County).	The catchment area includes all of Hamilton County in Ohio and Kenton, Campbell, and Boone Counties in Northern Kentucky, including the central metropolitan portion of the greater Cincinnati region.	The project includes two distinct areas: Wood, Pleasants, Wirt, Richie, Jackson and Tyler counties in central-western WV and Ohio, Wetzel, Marshall and Brooke counties in the panhandle of northwestern West Virginia.
Program Staffing (April 31, 1991)	Total Staff: 23.8 FTE	Total Staff: 26.6 FTE	Total Staff: 20.0 FTE	Total Staff: 16.1 FTE
Service Environment	Community spokespersons rated the long term care system as well developed.	The two urban long term care systems were rated as well developed; the rural area rated fair.	Community spokespersons rated the long term care system as well developed.	Community spokespersons rated the long term care systems in both catchment areas as fair.
Demonstration Service Provision	MJHHA is the primary provider of direct services for the project. In addition, MAP contracts with 40 other providers.	In each of the catchment areas, the Consortium's sponsoring agency was the primary and preferred provider of services. In addition, MAP contracts with 157 other service providers.	With the exception of home care, the majority of the services offered under the demonstration are provided by one of the consortium members. There were 47 contracted service providers.	The two host agencies are the primary service providers for demonstration services. In addition, there were 16 service provider contracts in Parkersburg and 17 in Wheeling.
Program Census (April 31, 1991)	371 Treatment Clients	412 Treatment Clients	306 Treatment Clients	187 Treatment Clients
Case Management Activities	Case managers spent the most time in: service monitoring/follow-up (23%) and record keeping/data entry (17%).	Case managers spent the most time in: initial care planning (22.4%) and service monitoring and follow-up (22.0%).	Case managers spent the most time in: service monitoring (36%) and initial care planning (15%).	Case managers spent the most time in: record keeping/data entry (23.6%) and initial care planning (14.5%) (Parkersburg) and initial assessment (21.4%) and record keeping/data entry (16.6%) (Wheeling).
Demonstration Service Utilization Trends (2nd Qtr. 1991)	Clients using only case management fluctuated from 9-21% and declined to 10% by June 1991.	Clients using only case management fluctuated from 20-45% at all 3 sites, but declined to approx. 20% by June 1991.	Clients using only case management ranged from 22% to 33% and declined to 26% by June 1991.	Clients using only case management declined from 74% to 18% in Parkersburg and from 44% to 35% in Wheeling.

CLIENT AND CAREGIVER CHARACTERISTICS

The interim findings have focused on the characteristics of the demonstration program participants and their caregivers. This is done to assess the similarity between the samples assigned to the treatment and control groups. The primary reason for conducting a random assignment of applicants into these two groups was to assure observed and unobserved comparability between these groups at enrollment into the demonstration. The absence of systematic differences at baseline provides greater confidence in interpreting, as treatment effects, any systematic differences found at later measurement points. Randomization has achieved comparable groups within each model in virtually every measure tested. There is also a high level of comparability between the two models as well.

CLIENT DIAGNOSIS, DEMOGRAPHIC AND SOCIO-ECONOMIC CHARACTERISTICS

A broad range of cognitive disorders have been used to define the population eligible for this demonstration. The principal requirements were that the condition be irreversible and organic in nature. By far the most prevalent diagnosis among participants in this demonstration is that of Alzheimer's disease, accounting for two-thirds to three-fourths of the sample. As shown in Table 3, this is followed by vascular dementia, unspecified dementia, and dementia resulting from degenerative conditions (e.g., Pick's, Parkinson's and Huntington's diseases). There are only minor differences within and between models on the distribution of these diagnoses. The sample is predominantly female (about 60 percent) and white (88 percent). Differences between the models (but not the treatment and control groups within models) occur in the proportions black and other (i.e., Hispanic). There are no appreciable differences in educational attainment or income distribution between the models or treatment and control groups.

Health insurance coverage also shows little difference within models, but there are regional (and hence model) differences in the proportions eligible for Medicaid or Veterans Administation (VA) benefits, participating in health maintenance organizations (HMOs), and with Medigap supplemental coverage or retirement health plans.

Living arrangements and type of residence again reveal no differences within models at baseline. Persons living with a spouse is the most common group at baseline, but substantial numbers live alone or with relatives. Consistent with this, the vast majority of clients live in homes, condominiums, or apartments. Less than 10 percent live in congregate housing or assisted living facilities.

TABLE 3

CLIENT DIAGNOSIS
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Diagnosis[1]	Treatment (N=1438)		Control (N=1392)	
	n	%	n	%
Model A				
Alzheimer's Disease [a]	1017	70.7	927	66.6
Vascular Dementia	307	21.3	322	23.1
Dementia caused by:				
Degenerative disease[2]	122	8.5	123	8.8
Central Nervous System infection	3	0.2	3	0.2
Head trauma	13	0.9	20	1.4
Other dementia	154	10.7	141	10.1
Group & Diagnosis[1]	**(N=1642)**		**(N=1569)**	
	n	%	n	%
Model B				
Alzheimer's Disease	1215	74.0	1132	72.1
Vascular Dementia	373	22.7	323	20.6
Dementia caused by:				
Degenerative disease[2]	102	6.2	111	7.1
Central Nervous System infection	5	0.3	2	0.1
Head trauma	12	0.7	16	1.0
Other dementia	155	9.4	164	10.5

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between the two models, using X^2 test of significance

[1] Percentages do not sum to 100 because categories are not mutually exclusive.

[2] Includes diseases such as Pick's, Parkinson's, Huntington's.

CLIENT PHYSICAL AND COGNITIVE FUNCTIONING

The average age of the study population is almost 79. This is a very impaired group, averaging over 5 limitations in 10 activities of daily living (e.g., walking, transfers, grooming, bathing, eating, toileting) and more than 7 limitations in 8 instrumental activities of daily living (e.g., meal preparation, shopping, money management, housework). Table 4 shows the physical and cognitive functioning of the sample at study baseline and among the sample remaining after six months. Sample subjects in both models and treatment groups, at both baseline and six-months have essentially identical mean scores in a summation of some or maximum assistance needs for activities of daily living (ADL) and instrumental activities of daily living (IADL).

The Blessed Roth Dementia Rating Scale (BRDRS) and the Mini-Mental Status Examination (MMSE) were used to assess cognitive functioning. Within models there are no differences between treatment and control groups. Scores on both scales indicate that the average client has a mild to moderate level of dementia.

TABLE 4

CLIENT AGE AND FUNCTIONAL MEASURES TREATMENT & CONTROL GROUPS, BY MODEL

Group & Arrangement	Baseline				6 Month			
	Treatment		Control		Treatment		Control	
Model A	n	Mean	n	Mean	n	Mean	n	Mean
Age	1220	78.5	1170	78.6	1224	78.8	1172	79.2
ADL[1]	1187	5.5	1131	5.5	1014	5.4	939	5.4
IADL[1]	1226	7.4	1173	7.4	1031	7.5	973	7.4
BRDRS[2]	1230	7.9	1177	7.8	1083	8.9	1037	8.6
MMSE[3]	1356	14.2	1324	14.3	*	*	*	*
Group & Arrangement								
Model B	n	Mean	n	Mean	n	Mean	n	Mean
Age	1389	78.8	1290	79.4	1384	79.2	1291	79.7
ADL[1]	1350	5.7	1247	5.6	1121	5.9	1024	5.8
IADL[1]	1394	7.5	1296	7.5	1144	7.6	1038	7.5
BRDRS[2]	1393	8.4	1297	8.2	1200	9.2	1108	9.2
MMSE[3]	1528	13.4	1446	13.3	*	*	*	*

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

*Test not completed at 6-month follow-up. The construction of each scale includes only persons who answered all items in the scale.

[1] ADL and IADL scores are based on persons needing some or maximum assistance.

[2] BRDS. Values can range from 1 to 17. Higher scores are indicative of greater impairment. Five or more mistakes is indicative of some cognitive impairment. Scores between 7 and 12 are indicative of mild to moderate impairment.

[3] MMSE. Values can range from 1 to 30. Lower scores are indicative of greater impairment. A score of 12 or under indicates moderate to severe impairment, 13 to 23 indicates moderate to mild impairment.

CAREGIVER CHARACTERISTICS

Spouses and female children predominate as the primary caregivers for the demonstration's dementia victims. There are no meaningful differences in the distribution of any of these attributes between the treatment and control groups in either Model A or B with respect to the demographic and economic resources of the initial caregivers. Primary caregivers, with an average age of 74, are but a few years younger than the person they are helping. More than half are married, usually being the spouse of the victim; but a substantial number are single because of widowhood, divorce, or separation. As a group, caregivers have somewhat more education than those under their care. Consistent with their age, about 70 percent of the sample is not working. Among those who are working, the average number of hours of employment per week is 35. Reported incomes of this group suggest that about one-quarter receive less that $15,000 annually while one-third receive under $20,000. The balance is distributed across the income range. Perhaps reflective of the low to moderate income levels of the caregivers, only about a third of the non-spouses regularly contribute to the "care" of the patient.

From the standpoint of functional ability , a substantial proportion of the primary caregivers have difficulty performing such basic tasks as housework, shopping, preparing meals, or doing laundry. A number also have ADL limitations, particularly getting out of bed or chairs. Consistent with these attributes about 25 percent of the primary caregivers report their health as "fair" or "poor." Less than a third report "excellent" health. There are no meaningful differences among the study samples on these attributes.

CAREGIVER STRESS, BURDEN, DEPRESSION, AND EMPLOYMENT STATUS

Caregiver stress and burden can come from a variety of sources. Among these are the type and number of hours of care provided. As seen in Table 5, the average dementia victim was receiving between 100 and 115 hours of informal care per week at the time of enrollment into the demonstration. This is the equivalent of almost 16 hours daily. Primary caregivers, on average, claim to be responsible for about 80 percent of this care. Caregiving hours declined for both treatment and control groups among those surviving through the first six months of follow-up. During both periods there are no statistically significant differences between treatment and controls. There are minor differences between models however.

The level of caregiving and the hours involved appear to have produced, on average, a moderate level of "stress and burden" for the primary caregiver. There is no statistically significant change, on average, in this level of clinical classification after 6-month follow-up.

Clinical depression has been used as another indicator of effects from caregiving. The study population is, on average, just below a level which would define probable depression. While there is no difference between the samples at baseline or after the 6-month follow-up, it should be noted that almost half the primary caregivers are above the threshold value of 5.0 on the Geriatric Depression Scale.

Adult Day Care

There were large differences in the use of adult day care by model and by groups. Forty-two percent of the Model B treatment clients were using adult day care compared to 25 percent of the Model A treatment clients. In both models, the proportion of control group members using this service was about half the treatment group level.

Out-of-Home Respite Care

This service was very infrequently used in any of the demonstration communities. Fewer than 5 percent of either treatment group or their controls reported using this service during the first six months of the evaluation. The major reason reported for non-use of respite care was that the service was not needed.

Personal Care Services

Personal care services were used by fewer than half the cases. Persons in the treatment groups were about 20 percent more likely to be using this service than those in the control groups. Model B clients were about 10 percent more likely to use this service than those in Model A. Among those not using this service, the major reasons cited for non-use were that the services were not needed (70 percent or more), not affordable, not available, or the client could not adapt. Awareness of the service was slightly higher among treatment group members, and affordability slightly less a problem.

Homemaker Chore Services

In both Models approximately one-third of the treatment group used homemaker chore services compared to approximately one-fourth of the control group. For all groups the primary reasons cited for non-use of homemaker chore services was that the service was not needed. Slightly more control group clients than treatment clients, in both Models, reported that the services were not affordable.

Companion Service

In most communities this service complements the in-home assistance of a homemaker or chore worker by providing shopping assistance, escort or transportation on other errands, and by offering limited in-home client supervision. Companions were used by one-fifth of the control group caregivers. Use rates were 50 to 100 percent higher among those receiving demonstration services. Model A cases more frequently used this service. This may in part be a function of price: companions are relatively less expensive than day care or home care and may be used as alternatives to these other services when monthly benefits have a lower reimbursement level. The reasons for not using companions were generally similar

CLIENT/CAREGIVER SERVICE USE

To obtain more understanding of service utilization among clients and their caregivers a series of questions were asked about six of the potentially most needed/beneficial services reimbursed under the demonstration: adult day care, respite care, personal care services, homemaker chore services, companion service, and case management services. For each service we obtained reasons for non-use of services (for non-utilizers of the service). These data were compiled for the first time at the 6-month follow-up.

TABLE 5

CAREGIVER AGE, HOURS OF CAREGIVING, STRESS & BURDEN, AND DEPRESSION TREATMENT & CONTROL GROUPS, BY MODEL

	Baseline						6 Month					
Group & Measures	Treatment			Control			Treatment			Control		
	Total	Mean	SD	Total	Mean	SD	Total	Mean	SD	Total	Mean	SD
Model A												
Age	1426	73.6	19.6	1380	74.5	18.6	1224	74.7	18.4	1172	75.2	18.1
Primary cgvr hours	1425	88.7	57.2	1380	84.2	58.2	1128	57.5	49.9	1093	55.7	52.4
Second cgvr hours	1436	20.7	83.2	1391	18.2	61.0	1117	16.8	22.0	1078	16.9	22.9
Total cgvr hours	1437	108.6	96.6	1391	101.8	81.2	1134	73.7	54.4	1099	72.0	59.0
Stress & burden[1]	1416	15.2	9.3	1368	15.0	12.2	1139	14.7	20.1	1103	14.7	28.2
Depression[2]	1415	4.3	3.2	1366	4.2	3.2	1135	3.9	3.3	1095	4.2	3.5
Group & Measures	Treatment			Control			Treatment			Control		
	Total	Mean	SD	Total	Mean	SD	Total	Mean	SD	Total	Mean	SD
Model B												
Age	1635	74.3	19.5	1555	74.7	19.1	1384	74.6	19.4	1291	75.0	19.4
Primary cgvr hours	1619	93.5	59.6	1547	92.7	59.7	1249	64.5	54.3	1167	59.6	54.2
Second cgvr hours	1633	23.0	82.4	1558	21.2	75.1	1221	15.2	21.8	1150	15.1	20.5
Total cgvr hours	1635	115.6	96.4	1562	113.0	92.5	1267	78.2	60.1	1186	73.3	59.4
Stress & burden[1]	1600	15.6	9.8	1533	15.6	8.5	1266	15.9	27.9	1186	15.9	36.2
Depression[2]	1598	4.6	3.4	1531	4.6	3.3	1265	4.7	3.6	1183	4.7	3.6

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between models at baseline, using X^2 test of significance
[c] $p < .05$ between models at 6-month follow-up, using X^2 test of significance

[1] Low stress & burden: 0-8; Moderate stress & burden: 9-16; Severe stress & burden: 17 or more. Possible range: 0 - 36. Zarit, Reever & Bach-Peterson (1980).

[2] Scores greater than 5 reflect probable depression. Possible range: 0 - 15. Sheikl & Yesavage (1986).

to the other in-home support services: "not needed," "caregiver/client could not adapt or did not like," or it was "unaffordable."

CASE MANAGEMENT SERVICE USE AND SATISFACTION

Case management is the cornerstone of the demonstration. Over 95 percent of all demonstration plan members in Models A and B reported the use of this service. Those not "using" the service generally described it as not being needed. Use rates were substantially lower among those in the control groups. This was by design. Each demonstration site was limited in the proportion of cases it could enroll who were receiving "intensive" case management at the time of application. This restriction was used in order to minimize the occurrence of cases who were receiving services that essentially replicated the demonstration's intervention. In most sites this made many Medicaid recipients ineligible for the demonstration, since they were receiving similar levels of case management and more extensive benefits under that program. Most control group cases not using case management were "unaware of its availability" or reported it as "not being needed."

There is some difference between the two demonstration models with respect to frequency of contacts with case managers. Model A, with a planned ratio of 1 case manager to 100 clients, has fewer phone contact and in-person contacts than the Model B counterpart, with it ratio of 1:30. More frequent case manager-initiated contacts appears to stimulate, rather than reduce, caregiver initiated contacts. The Model A plan appears to offer a comparable frequency of contacts to that received by the controls.

Satisfaction with case management is relatively high, especially among those in the Model B program, where almost 75 percent are "very satisfied." Over 95 percent of all case management users report being "very satisfied" or "satisfied."

NURSING HOME UTILIZATION

Persons could not be nursing home residents at enrollment. The treatment and control groups begin to diverge, but only slightly from each other at the 6-month follow-up. Both groups show decreases in the proportion living alone or with spouses, and increases among those in nursing homes or assisted living. Table 6 provides more detail on the sample between study baseline and April 30, 1992. During that interval about 28 percent of the sample entered a nursing home. Throughout this period, the treatment group, on average, is in the program about 20-30 days longer than the control group before nursing home admission—a possible positive program effect. Treatment group cases, on average, also have 20-40 fewer days in the nursing home before death, another possible program effect. Almost three-quarters of those admitted to nursing home in both groups are still nursing home residents. We urge caution in drawing conclusions from these initial changes and comparisons between models since no adjustments have been made for client condition severity or the types of support systems available.

TABLE 6

NURSING HOME (NH) UTILIZATION BETWEEN DATE OF ENTRY AND 4/30/92 BY MODEL AND TREATMENT GROUP

	Model A	Model B
Number Persons in Sample[a]		
Treatment	1378	1557
Control	1328	1495
Percent Admitted to NH		
Treatment	27.6	28.7
Control	23.8	27.0
Mean Days in Program Before NH Admission		
Treatment	287.0	295.2
Control	274.0	268.0
Mean Days in NH Before Death		
Treatment	146.2	138.9
Control	165.8	181.2
Percent of NH Admissions Still in NH		
Treatment	76.7	72.2
Control	84.6	77.8

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] Sample has been adjusted to remove all cases who died or were in NHs within 31 days after randomization into the demonstration.

Chapter One

ALZHEIMER'S DISEASE AND RELATED DISORDERS AS A PUBLIC POLICY ISSUE

The Medicare Alzheimer's Disease Demonstration (Section 9342 of Public Law 99-509 [OBRA-86]) was mandated by Congress in 1987 in response to growing public awareness of the problems in obtaining adequate and appropriate services to assist in the care and management of demented persons. The project is designed to provide Medicare beneficiaries with an array of services that would not normally be reimbursed under the Medicare program (e.g., case management; in-home services such as homemaker chore and personal care; and community-based services such as adult day care), and to determine the effectiveness, cost, and impact of these services on the health status and functioning of persons with Alzheimer's disease and related disorders.

The demonstration program was designed by Mathematica Policy Research, Inc. (MPR) under contract with HCFA. On October 1, 1989 HCFA's Office of Research and Demonstration contracted with IHA, UCSF to conduct an evaluation of the demonstration. The period of performance for the evaluation was originally scheduled for 45 months but was subsequently extended an additional 12 months to cover the period of time that Congress granted an extension for demonstration services. This report fulfills a requirement of the legislation establishing the demonstration that specified the submission of an interim report to Congress describing the demonstration and the early experience of the sites in implementing the interventions being tested.

The first chapter of this interim report provides background information on problems faced by persons with Alzheimer's disease and their caregivers. Chapter Two describes the demonstration goals and program design. Chapter Three specifies the major research questions and hypothesized demonstration impacts. The evaluation design is presented in Chapter Four including the research design, the data collection instruments and procedures, the study sample, and sample attrition. Chapter Five addresses program implementation issues that also potentially impact the evaluation outcomes. Chapter Six provides site descriptions of the eight demonstration projects. The final chapter presents the preliminary findings including baseline characteristics of the study sample and analyses of client and caregiver outcomes, and service satisfaction at the 6-month follow-up.

BACKGROUND

This chapter provides an outline of Alzheimer's disease and its effects on its victims and those who provide care for them. Included is an overview of the epidemiology of dementia and Alzheimer's disease, followed by a review of relevant literature describing the costs of the disease to society. Patterns of service utilization by persons with dementia and their caregivers are also discussed, with a focus on gaps in our understanding of the reasons why people use or fail to use services to help them with the long term care of persons with dementing disorders.

Alzheimer's disease is a progressive dementia primarily occurring in the later years of the life span, but it may appear as early as age 40. Persons with Alzheimer's disease are characterized by disorientation as to time, place, and person; deterioration of personality; and physical incapacitation. The onset and progression of the disease is characteristically gradual and follows a deteriorating course over time. People who performed routine daily activities have difficulty with cognitive and functional tasks as the disease progresses and ultimately rely on others for assistance, placing substantial financial and emotional burdens on the afflicted patient, his/her family, and the community.

Alois Alzheimer was the first to describe the presence of neurofibrillary tangles in the cerebral cortex which were associated with senile plaques. There have historically been contentions whether these findings conclusively demonstrated the existence of a disease that was different from other diseases resulting in dementia (Critchley, 1933; Boyd, 1936; Marchand, 1940; Green, 1952; Sjogren, 1952; Thompson, 1969). Distinctions between forms of the disease subsequently emerged, with the age of onset of 60 (Roth, 1981) or 65 (Katzman & Karasu, 1975) years used to distinguish senile from presenile forms. It has been emphasized, however, that there is little reason to make such a differentiation based upon age of onset (O'Brien, 1977) or upon clinical or pathological grounds (Newton, 1948; Neumann & Cohn, 1953; Terry & Wisniewski, 1975). Suggestions have been made to eliminate distinctions between senile and presenile forms of Alzheimer's disease (Katzman & Karasu, 1975), partially as a result of biostructural studies of its pathological characteristics (Terry 1963; Kidd, 1963). The clinical definition, correct diagnosis, and determination of age of disease onset continue to be problematic (Roth, 1981; Katzman & Karasu, 1975; Cohen & Dunner, 1980; Eisdorfer & Cohen, 1980; Gurland, 1981; Gurland et al., 1982; Gurland & Cross, 1982; Gurland & Toner, 1983; Reisberg, 1983; Khachaturian, 1985). Senile dementia of the Alzheimer's type has only recently been recognized as a neuropsychiatric problem which has its highest incidence among the elderly (Katzman, 1976). Diagnostic proposals have distinguished between possible, probable and definite clinical classifications of the disease (McKann et al., 1984).

The year 1976 marked the first time the potential public health implications of Alzheimer's disease were clearly outlined in the literature (Katzman, 1976). Since that time, research related to the disease has increased dramatically (U. S. Congress, 1987). This expansion has primarily been due to the efforts of such organizations as the Alzheimer's Association and the National Institute on Aging which have increased awareness of the disease, as well as stimulated funding for research (Fox, 1989). Numerous publications resulting from biomedical research have appeared (Cf., Terry & Katzman, 1983; Katzman, 1986; U. S. Congress, 1987), giving rise to a number of theories regarding the etiology of the disease (Wurtman, 1985).

While there are no definitive statistics, it is clear that the prevalence of dementia is increasing if only because life expectancy is increasing. It is estimated that 5 percent of the population over 65 years of age suffer from severe dementia and 11-12 percent suffer from mild to moderate dementia (Cartwright et al., 1984). The estimated prevalence of severe dementia for persons aged 85 or older (the oldest-old) is much higher, ranging from 25 to 45 percent (U. S. Congress, 1987). By the year 2000, 1.3 million cases of severe dementia are projected in the oldest-old age group alone and a total of 2.4 million cases among persons aged 65 or older (U. S. Congress, 1987). Current estimates suggest that 50-60 percent of the institutionalized elderly population in the United States are demented (National Center for Health Statistics, 1991; (Rovner et al., 1986; Katzman, 1985; Hu et al., 1984; Nielson & Robinson, 1984; National Center for Health Statistics, 1979). By the year 2000 it is estimated that the number of persons with dementia is expected to increase by 60 percent (Weiler, 1987), and that by the year 2040 7.4 million people will suffer from severe dementia (U. S. Congress, 1987). The prevalence of Alzheimer's disease is estimated at 3.75 million cases in 1990, representing slightly over 10 percent of the total population aged 65 or older; 9 million Alzheimer's disease cases are projected by the year 2040 (Evans, 1990). The estimated prevalence of severe dementia, including Alzheimer's disease, for persons aged 85 or older (the oldest-old) is much higher, ranging from 25 to 45 percent (U. S. Congress, 1987). Almost half of all nursing home patients have severe dementia (Rovner et al., 1986; National Center for Health Statistics, 1991).

While the health care delivery system is able to meet some of the needs of Alzheimer's disease patients for medical care, a large share of the burden in caring for such patients falls on relatives and friends. Since Alzheimer's disease is more prevalent in the older age categories, the medical care needs of the majority of persons with the disease are generally met through the Medicare program. However, Medicare primarily covers acute care services or in-home care associated with an acute hospitalization, and dementing disorders such as Alzheimer's disease rarely, in themselves, require hospitalization (Helbring, 1985). The chronic impairments that accompany dementing diseases instead require long term care that is usually provided either in skilled nursing facilities for the most severely demented, or in the community by the demented person's informal care system. It has been estimated that " for every person residing in a nursing home, as many as two to three individuals who live in the community require an equivalent amount of care, which they are currently receiving, if at all, primarily from informal sources" (HCFA, 1981).

While the Medicaid program pays for a substantial portion of the institutional care of older demented persons, the coverage of community-based long term care is much more sparse unless associated with a Medicare waiver program that specifically targets those with chronic impairments such as Alzheimer's disease who require long term care. Even when such programs exist, they are generally limited to a handful of states, and participant income restrictions limit the availability of services to a rather small proportion of the population who may need some type of long term care.

For example, a study by Rice et al. (1993) found that, on average, Medicare covered 12 percent of the total cost of formal care (including hospital, nursing home, physician visits, medications, medical supplies and social services) provided to community resident persons as a result of Alzheimer's disease, while Medicaid covered less than 1 percent of the costs. Private payments for formal care are considerably higher than public payments -- 65 percent (mainly self-pay) compared with 35 percent (mainly sources other than Medicare and Medicaid, such as VA and state, county, and city-funded services).

Research suggests that family members are generally the primary providers of informal care to the frail aged (Shanas,1979) and that the spouse and adult children are the usual caregivers (Cantor, 1983; Johnson & Catalano, 1983). Information on the amount of time that family and friends devote to caring for patients with Alzheimer's disease has been difficult to obtain. Few studies have examined the issues and costs related to the provision of informal care services such as household chores, personal care tasks, and accompanying the impaired relative on errands and to the physician.

Although not specifically focused on Alzheimer's disease, a study by Paringer (1983) found that three-fourths of the functionally dependent, non-institutionalized elderly relied primarily on family and friends for care. These findings also suggested that time demands placed on informal caregivers were directly related to the ability of the impaired person to perform basic ADLs, ranging from 9 to 27 hours of informal care per week. Based on foregone market earnings, it was estimated that the cost of informal care alone in 1979 was from $7.2 to $18.0 billion dollars (Paringer, 1983).

While data on the costs of medical and social service care are relatively easy to gather for most diseases, this is not the case for Alzheimer's disease. The primary difficulty in obtaining accurate and consistent health care data on such patients is the difficulty in diagnosis and poor reporting of the disease. Diagnosis is dependent upon the exclusion of other likely causes of dementia (Hutton, 1981). While there have been significant improvements in the reliability of diagnoses in general (Katzman, 1986), there are still variations in reporting accuracy and prevalence. Even given these limitations, some researchers have developed estimates of the costs of health care for dementia patients. Anderson (1981), for example, estimated the annual medical care costs for the elderly population with dementia to be

$5,329 per person.

Huang, Cartwright, and Hu (1988) estimated both the direct social and medical care costs and the indirect informal care costs of senile dementia in general rather than Alzheimer's disease alone. Their estimates were based on secondary data and included costs associated with lost productivity and premature death. Their estimates of medical and social service costs amounted to $13.26 billion and of community home care (caregiver services) to $31.46 billion nationally. Inflated to 1990 dollars, medical and social service costs amount to $20 billion and caregiver service costs amount to $38 billion, for a total of $58 billion.

The work of Huang, Cartwright and Hu highlights the importance of informal care for people with senile dementia, including Alzheimer's disease. But they did not closely track over an extended period of time the activities of informal caregivers to measure those actually performed for people with the disease. Nor did they track the provision of informal care and its associated costs for demented persons admitted to institutions. This is important because caregivers continue to provide informal care up to and including the period after placement. Hay and Ernst (1987) examined the costs of caring for persons specifically with Alzheimer's disease using secondary data sources and including costs associated with medical care, lost productivity, and informal care. They estimated the costs to society for all persons first diagnosed with Alzheimer's disease in 1983 to be between $27.9 and $31.2 billion.

LONG TERM CARE SERVICE DELIVERY TO PERSONS WITH DEMENTIA AND THEIR CAREGIVERS

Since the early 1960s many formal, non-institutional medical, social, and health related services for the elderly have been provided under the rubric of "community-based long term care." With the implementation of the Medicaid, Supplemental Security Income, and Medicare programs, coupled with the growing number of elderly persons, service demand has increased and has resulted in rising public and private costs for community-based long-term care. These costs are expected to continue to increase into the next century because of inflation and an increasing proportion of the population who will become aged. One population group that has the potential for high long-term care service utilization are persons with Alzheimer's disease and related disorders. Because of the progressive course of many dementing disorders that result in increasing incapacity (Shore & Good, 1987; Zarit, 1986), it is likely that levels of formal community-based service utilization for persons with these types of diseases will increase over time.

While both the role of informal care in assisting the demented elderly and the effect of such care on caregivers has been documented (Hirschfeld, 1979; Mace et al., 1980; Zarit et al., 1980; Levine et al., 1983; Green et al., 1982; Gilhooly, 1984; Ory et al., 1985; Morycz, 1985), the role of the formal system has received less attention. Although early research focused on general service utilization (Rosenstock, 1966), recent research has emphasized the utilization of formal community-based long-term medical and health care services (Wan & Soifer, 1974; Branch et al., 1981; Coulton et al., 1982; Eve, 1982; Wan, 1982; Wan & Arlins, 1983; Coe et al., 1984; Coe et al., 1985; Wan, 1987; Krause, 1988).

Research has focused on the elderly's utilization of health care and social services (Coulton & Frost , 1982; Branch et al., 1981; Shapiro & Roos, 1982; Krout, 1983; Soldo, 1985; Harel, 1985), but few studies have been conducted specifically on the service utilization patterns of persons with dementia. Researchers have, however, examined the degree to which institutional care is used by demented persons. Data suggest that persons with dementia use a disproportionate amount of medically oriented skilled nursing care in that it is estimated that over 50 percent of nursing home residents have some form of dementia (Arie, 1977). Not only does society face a substantial burden from the costs of institutional care for Alzheimer's patients, but the generally unseen costs to caregivers have significant effects as well (Brody et al., 1984; Cartwright et al., 1984; Hu et al., 1986). Because the course of chronic dementing illnesses are progressive, and most persons with these diseases live outside institutions for extended periods, community-based service utilization patterns specific to this population must be explored if policy formulation is to be effective (see Butler & Newacheck, 1981).

The model most often used to understand health service use among the elderly was developed by Andersen and Newman (1973). They contend that the elderly's health service utilization patterns are a function of need (perceived or diagnosed illness level); predisposing factors such as age and gender; and factors that enable an individual to access services such as transportation (Andersen and Newman, 1973). Many studies have been conducted to test this hypothesis and have found relationships between factors such as age and service use (Snider, 1981). When multivariate analysis has been conducted, however, the evidence of illness or disability (need) has accounted for most of the *explained* variance in service use, with predisposing and enabling factors having a negligible effect (Evashwick et al., 1984; McAuley and Arling, 1984; Coulton and Frost, 1982).

But only a small proportion of the variance in service use is explained, even by need. Several relatively recent studies are able to explain only 7-9 percent of the variance in service use with this factor (Wan, 1982; Branch et al., 1981). Many models or approaches have been recently advanced to fill this void, but few have been rigorously tested as yet. But more importantly, there are special issues for people with Alzheimer's disease that will certainly have an effect on their service utilization patterns.

First is the problem of the mental status of patients. As the judgment of a person with Alzheimer's disease deteriorates, an increasing amount of decision-making must be undertaken by the patient's caregivers. These decision-makers are often family members who may or may not exhibit the same service utilization patterns as the older individual him/herself (Stone and Cafferata, 1986).

A second problem complicating research efforts is the lack of available services for people with Alzheimer's disease. While many community based long term care services are being developed throughout the country, often these are not appropriate for, or do not accept, persons with Alzheimer's disease and related disorders. A survey of adult day health care centers throughout the Nation found that only 5 percent of the sample oriented their services to persons with Alzheimer's disease. Overall, the study found that of an estimated 2 million people with dementia in the United States, only 3,000 were currently being served in day care programs (Mace and Rabins, 1984). Other research indicates that standard public assistance programs such as homemaker/chore are so limited in both quality and quantity of available service that some caregivers report it does not help to use them (Hooyman, Gonyea and Montgomery, 1985; Kaye, 1985).

A third problem is the lack of reimbursement for health care services for people with Alzheimer's disease. A national survey whose respondents were caregivers of the elderly found that the majority (57.1 percent) reported adjusted family incomes in the low to middle range (Stone and Cafferata, 1986). Nonetheless, surveys indicate that most services used by these people have to be privately purchased (U. S. General Accounting Office, 1977; Doty, 1985). Except in states that have established Medicaid waiver programs to address the long term care needs of the chronically ill, care is generally available only when a family has decided to institutionalize the patient.

Because of these factors, service utilization patterns may be affected to an unusual degree in this population by issues of cost. One study on support groups concluded "it was often apparent during group sessions that caregivers needed (but did not use) concrete assistance such as in-home chore services, sitters and home health care which they could not afford and were not eligible for on any reduced charge or fee basis" (Haley, Brown and Levine, 1987:381).

Finally, research on service utilization has proceeded with difficulty due to the complexity of the relationship between informal care and the supplemental use of formal services. Morycz (1985) found, for example, that for caregivers of people with Alzheimer's disease, instrumental informal support (e.g., "hands on" caregiving such as personal care versus taking care of bills or errands) could reduce the likelihood of patient institutionalization through a reduction of caregiver burden. Other studies have been inconclusive, however. There is some evidence that formal services do not decrease burden, even if provided in the form of respite services for caregivers (Ory et al., 1985). That these two systems, the informal support network and formal services, interact is now accepted in the literature. How they interact, particularly with the Alzheimer's disease population, is still unresolved.

While research proceeds on the effectiveness (and cost effectiveness) of formal services in delaying the eventual institutionalization of persons with Alzheimer's disease, it is equally important to determine why available services are currently underutilized. Ory et al. (1985) notes that "little attention is given to the ways in which families utilize - or fail to utilize - both informal and formal support services to care for Alzheimer's disease patients" (Ory et al., 1985:634). They note results from an earlier study where a substantial portion of people with dementing disorders who clearly had service needs were not recipients of any service. It is clear that "need" alone is a necessary, but not sufficient, basis for formal service utilization by caregivers of people with Alzheimer's disease.

UTILIZATION OF FORMAL SERVICES BY CAREGIVERS

Much of the research in this area is characterized by non-probability samples. Generally, caregivers have been identified through their membership in support groups or through a clinic that treats dementia patients (Chenowith and Spencer, 1986; Filinson, 1985; Barnes at al., 1981). These studies have noted that low utilization of available services for persons with Alzheimer's disease may be related to cost and the inappropriateness of the service provided. The studies also indicate that low service utilization rates for this group are associated with stress related to coping with any additional factors, including the presence of an in-home worker, in an already stressful situation (Filinson, 1985; Kaye, 1983).

Caserta et al. (1987) notes that little is known about the utilization patterns of caregivers of dementia patients when services are available. From anecdotal reports by caregivers and the few available research studies, several general impressions can be garnered. It appears that the degree of involvement of the caregiver both with the patient and available resources (e.g., income, information, informal support) must be examined in relation to service utilization. There is also some evidence that caregivers may have difficulty determining what their needs actually are (Caserta et al., 1987; Zarit, Todd and Zarit, 1986).

Perhaps more for caregivers of persons with Alzheimer's disease than for other caregivers of the frail elderly, the decision to utilize or not utilize formal services (especially respite care) may be related to the presence or absence of a variety of factors relevant to the caregiving experience. One factor that may influence this decision is the presence of emotional burden. Although the available empirical research is fragmentary, evidence suggests that providing care for those with Alzheimer's disease can exact a psychological and physical toll on caregivers. In an effort to clarify the issue, Poulshock and Deimling (1984) have suggested distinguishing between "impact," that refers to relatively objective changes in the caregiver's status such as alterations in physical or mental health and social activities, and "burden" that refers to the subjective experience of stress. Reductions in the health status of caregivers have been widely described (Sainsbury and Alencon, 1970; Arcibald, 1982; Farkas, 1980; Barnes et al., 1981; Haley et al., 1987; Moritz, 1987), as have changes in mental health status, especially related to depression (Eagles, 1987; Gilhooly, 1984; Moritz et al., 1989).

Cohen and Eisdorfer (1988) reported that 55 percent of a sample of caregivers who did not participate in support groups or have access to respite care experienced clinical levels of depression. Studies have also documented decrements among caregivers in life satisfaction, well-being or similar constructs (Gilhooly, 1984). A number of studies have documented the subjective experience of burden in caregivers (Zarit et al., 1980; Zarit et al., 1986; Wilder et al., 1983; Cantor, 1983), while other studies have identified family conflicts that have been associated with caring for a demented person (Naiderehe and Fruge, 1984; Wilder, Tans and Bennett, 1983; Rabins, Mace and Lucas, 1982).

A number of other characteristics have been examined to account for variations in caregiver impacts. There is evidence to suggest that female caregivers experience greater negative mental health impacts (Fitting et al., 1986; McKinley and Tennistedt, 1986), while other studies report no gender differences (Robinson, 1983; Zarit, Reever and Bach-Peterson, 1986). Based on a community sample of spouses who live with cognitively impaired elderly persons, Moritz et al. (1989) report that husbands evidenced more depressive symptomatology than wives as a function of the patient's level of cognitive impairment. Because of these discrepant findings, no clear statement can be made at this time regarding the effects of gender on caregiver impacts.

Investigators have also examined the consequences for caregivers of stresses and strains associated with providing care. Financial problems have been identified as having an impact on caregiver well-being and levels of depression (Cantor, 1983; Ory et al., 1985; Thompson and Doll, 1982; Moritz et al., 1989). There is also evidence to suggest that reductions in employment outside of the home can be another result of caregiving (Brody, 1985). There is general agreement, however, that accessible social support mitigates negative impacts associated with caregiving (George and Gwyther, 1986; Scott and Roberto, 1986).

Investigators have also attempted to examine levels of caregiver impact associated with particular patient characteristics such as cognitive impairments, functional impairments and problematic behaviors. Studies that have examined the relationship between patient functional impairments and caregiver functioning have demonstrated positive relationships (Deimling and Bennett, 1986; Poulshock and Deimling, 1984; Wilder, Teresi and Benett, 1983), but other studies have indicated, for example, that functional impairment in the wife does not account for increased depression scores in the husband (Moritz et al., 1989). Other studies have found that cognitive functioning, but not ADL scores, predicted subsequent institutionalization (Fisk and Pannill, 1987; Colerick and George, 1986). Generally speaking, patient characteristics have an effect on caregiver reports of subjective burden, but the contribution of different patient characteristics on caregivers is still questionable.

This demonstration provides an important opportunity to assess many of the issues reviewed above, especially related to the effectiveness, cost, and impact on health status and functioning of both patients and caregivers through the provision of a wide array of services for persons with Alzheimer's disease and related disorders. The demonstration also allows sites to fill current gaps in the provision of services to this population, as well as improve reimbursement mechanisms for provided services, both of which have been routinely reported in the literature as barriers to service utilization.

Chapter Two

DEMONSTRATION GOALS AND PROGRAM DESIGN

Because of limitations in Medicare coverage of long term care for people with chronic dementing disorders, coupled with the variable patchwork system of long term care services available in states through Medicaid or Medicaid waiver programs, Congress established the Medicare Alzheimer's Disease Demonstration. The broad goal of the demonstration is to assess the effect on demented persons and their caregivers of increased access to an expanded range of Medicare-funded community-based long term care services.

The demonstration is designed to address two of the major difficulties encountered by caregivers. First, the need for community-based services that are geared toward meeting the care needs of demented persons. Second, because of the long term care coverage limitations of the Medicare and Medicaid programs, the creation of reimbursement schemes that will increase access to these services. The demonstration addresses these two needs by providing sites the flexibility to deliver a number of community-based services oriented toward persons with Alzheimer's disease or a related dementia through a case managed system approach, and by providing reimbursement for services that are not normally available under current Medicare or Medicaid reimbursement schemes.

The basic goals of the demonstration are fourfold and include: (1) ensuring the development of an effective network of community-based services that address the medical, mental health, and social support needs of the cognitively impaired and their caregivers; (2) providing education and support services to caregivers to minimize stress associated with caregiving and to enhance caregiving skills; (3) creating opportunities for demented persons to be cared for in preferred environments and supporting the use of the most appropriate level of care whether in institutional or community settings and; (4) ensuring that the services provided are cost-effective and that the costs of care are equitably distributed. If these goals are met by the demonstration, then our understanding of the dynamics of the caregiving situation and the effects of increasing access and reducing cost barriers to services that are most appropriate to assist in the care of demented people in the community will be significantly enhanced.

Within these broad goals, demonstration sites seek to: 1) provide a range of affordable, high quality community services; 2) provide information and assistance to clients and caregivers that will allow them to access these services by arranging and paying for a portion of their costs; 3) provide assistance to caregivers to help them cope with caregiving responsibilities and; 4) provide support and assistance to caregivers to make an appropriate decision to institutionalize patients or keep them at home.

The demonstration intervention and evaluation was designed by MPR under contract to HCFA. MPR also worked closely with HCFA in developing guidelines for selecting sites, working with the selected sites in the initial stages of implementing the demonstration, assessing the hypothesized impacts of the demonstration (discussed in chapter three), and developing the evaluation contract parameters. The centerpiece of the evaluation developed by MPR is an experimental design wherein participants are randomly assigned to either the treatment group which receives the expanded range of demonstration services and case management or the control group which receives none of the case management or other services. This type of evaluation design helps to insure that any differences observed between the treatment and control groups can reasonably be attributed to the interventions being tested. Hypothesized differences between the treatment and control groups will be examined in terms of the impact of the demonstration on demented persons, their caregivers, service utilization patterns, and expenditures.

Case management services are a centerpiece of the intervention because caregivers of demented persons, especially if the onset of dementia is relatively recent, are expected to have little experience in accessing services that can assist in the provision of care for the client. Because of the relatively low formal social and health service utilization rates of elderly people in general and demented people in particular, aggressive outreach efforts by demonstration sites were necessary to identify those who are eligible to participate in the program. We will more fully explore this issue in subsequent chapters of this report.

Criteria for enrollment in the demonstration developed by MPR were that all eligible applicants must have a diagnosis of an irreversible dementia, be enrolled in both Parts A and B of the Medicare program, and reside in the demonstration site's catchment area. Applicants that meet the aforementioned criteria and who reside in a nursing home or hospital will be eligible to participate in the demonstration if discharged within one month of their application. A number of conditions were added to both the eligible and ineligible lists of disorders that were not specified in the MPR design. Although many of the diseases that were added produce dementia in only a small percentage of cases, they were included so as to provide a more refined list of eligible and ineligible disorders (Katzman, Lasker and Bernstein, 1988) to assist community physicians in referring individuals to the demonstration.

Because most of the data collected under the demonstration are obtained from the patient's primary informal caregiver, most participants have a source of informal assistance. Patients without an informal caregiver participate in the demonstration, provided that a formal support system has been developed and adequate formal assistance is provided to allow the participant to remain in the community.

Medicare beneficiaries are eligible for participation in the demonstration if, in addition to the other three criteria, the patient's physician provides information requested on a Physician Referral Form. The information requested on this form includes the specific dementia diagnosis(es), whether alcohol is a significant contributing factor to the patient's dementia, information concerning the patient's medical history, medications the patient is currently taking, and results of specific laboratory tests, if available.

Two basic case management models are being tested under the demonstration and provide service delivery variation along two continua: the type of services that are provided (across site variation is due to local service system differences) and the intensity of service provision (variation is due to differences in cost caps between the models). Case management is the centerpiece of both models and the design of the demonstration allows for the provision of services to persons with Alzheimer's disease and related disorders that are not otherwise available or reimbursed by existing mechanisms of community-based long term care service provision.

The two models that are being tested vary along two dimensions: the case manager-to-client ratio and the level of the allowable per-month expenditure cap for each client. A comparison of the basic characteristics of the two models is outlined below:

Model A	**Model B**
Low-Expenditure Cap	*High-Expenditure Cap Model*
1:100 case manager-to-client ratio	1:30 case manager-to-client ratio
Provides in-home services including homemaker/chore, personal care, home health, skilled nursing, as well as other services	**Same**
Provides medical, social or Alzheimer's-specific adult day care	**Same**
Other community services	**Same**
Incorporates an overall "low" cap on per patient expenditures per month	Incorporates an overall "high" cap on per patient expenditures per month

These models were chosen by MPR because case management is seen as a key service component for demented persons and their families. Both models also allow for the provision of a wide range of services, and the differences in case management intensity and service expenditure caps provide a test of models at different funding levels. Demonstration sites are reimbursed for case management at cost, 80 percent for direct services, and 100 percent for direct services if the demonstration participant is also a Medicaid recipient. Except for Medicaid participants, patients and families pay for the remaining 20 percent of service costs. The cost-sharing approach is expected to provide patients and/or families with an incentive for cost consciousness.

The monthly cap amounts are adjusted for geographical cost variations and range initially from a low of $300 per month under Model A to a high of $500 under Model B. Sites were instructed to use public (e.g., Medicaid, Title XX, Title III) or private (e.g., United Way, Catholic Charities, Jewish Federation) sources of funding for community health and social services prior to the use of demonstration-supported services. Demonstration services could, however, be used to replace or supplement health or social services that clients or their family members pay for out-of-pocket.

The demonstration can pay for a wide variety of community-based long term care services, many of which are reimbursable under the Medicare skilled care benefit. However, under the regular Medicare benefit, skilled in-home services are provided in conjunction with an acute hospitalization episode and are designed to assist the patient in the post-hospitalization recovery period, not to assist in protracted long term care resulting from the effects chronic diseases. The services covered by the demonstration include the following:

- adult day care
- skilled nursing
- rehabilitation nursing
- therapies (i.e., speech, occupational, physical)
- home health aide
- homemaker/personal care
- housekeeping
- general chore (i.e., heavy cleaning)
- home repairs and maintenance
- companion (i.e., friendly visiting, incidental shopping and errands, telephone reassurance)
- companion for education and training (so caregiver can leave home to participate in education/training sessions)
- home delivered meals
- non-emergency transportation for client
- adaptive and assistive equipment
- medical supplies
- durable medical equipment
- consumable care goods
- mental health treatment
- caregiver education and training
- family counseling
- caregiver transportation to support groups
- case management
- medical assessment

A total of eight model sites were selected, four of which operate under Model A criteria and four of which operate under Model B criteria. The sites are located in different geographical regions of the United States and are listed below:

Model A Sites

Monroe County Long Term Care Program, Inc.
Rochester, New York

Carle Clinic Association
Urbana, Illinois

Northeast Community Mental
Health Center
Memphis, Tennessee

Good Samaritan Hospital and
Medical Center
Portland, Oregon

Model B Sites

Cincinnati Area Senior Services, Inc.
Cincinnati, Ohio

Wood County Senior Citizens Association
Parkersburg, West Virginia

Amherst H. Wilder Foundation
Minneapolis, Minnesota

Miami Jewish Home and
Hospital for the Aged
Miami, Florida

Chapter Three

RESEARCH QUESTIONS AND HYPOTHESIZED IMPACTS OF THE DEMONSTRATION

The design of the demonstration, with its flexibility in allowing a wide variety of services to be reimbursed under Medicare and its emphasis on case management, should allow for the generation of results that can be used to adequately assess the impact of the interventions on patients and caregivers. The major questions that the demonstration is designed to address include the following:[1]

1. What factors are associated with the cost-effectiveness and impact on health status of providing expanded services to Alzheimer's disease and related disorders Medicare beneficiaries and their caregivers?
2. In what ways do various services provided under the demonstration affect the functional status of clients and the well-being of their family members?
3. What are the effects of the provision of an expanded range of services, including caregiver support and counseling services, on caregiver burden?
4. What is the impact of expanded training for formal and informal caregivers on the quality of care and client well-being?
5. Do demonstration services delay or prevent the institutionalization of persons with Alzheimer's disease and related disorders?
6. What are the effects of alternative reimbursement caps on service utilization and on the distribution of the burden of cost for public and private payers?

The two models are expected to have similar impacts on clients and caregivers, but the magnitude of the impacts are expected to vary given differences in case management intensity and in the monthly reimbursement caps that are allowable per client. Because of its 1:100 case manager to client ratio and its lower allowable monthly service expenditure cap, we expect that clients and caregivers served under Model A will exhibit less dramatic changes in a variety of outcome measures than those served under Model B with its 1:30 case manager to client ratio and higher monthly expenditure caps.

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[1] An issue that was originally included in the MPR design work was whether community outreach efforts mandated by the demonstration assisted in the identification of previously unidentified persons with Alzheimer's disease and related disorders. Although it was originally envisioned that the demonstration would provide diagnostic work-ups for clients who may require one, the costs associated with this procedure was deemed to be too high given the monthly reimbursement caps. Although sites were free to pay for diagnostic work-ups, none were provided as a demonstration service. Since we relied on the applicant's physician to attest to the fact that a client had an irreversible dementia, we could not assess whether the demonstration assisted in the identification of previously unidentified demented persons.

IMPACTS ON CAREGIVERS

Measures of service provision and measures of burden and well-being are the two categories of outcome measures that will be analyzed in relation to informal caregivers. Measures of service provision include: (1) the types of care provided; (2) the frequency of care provision; and (3) percent of participants receiving informal care. Measures of caregiver burden include financial burdens; employment restrictions; and social participation restrictions. Measures of caregiver well-being include physical health status; mental health status; and financial resources. Because of increased access to services as a result of case management and monthly service expenditure caps, we expect that when compared to the control group, treatment group caregivers will exhibit lower caregiver burden and stress, fewer employment and social participation restrictions, better physical and mental health status, and less financial burden.

The impact of services provided under the demonstration may vary according to changes that occur in the client's and/or caregiver's situation. For instance, caregiver stress may increase if the patient begins to exhibit aberrant behaviors or if the caregiver becomes ill and finds it difficult to provide adequate care to the client. Such variations in client/caregiver situations are important to examine to more clearly understand the dynamics of the caregiving situation.

IMPACTS ON PERSONS WITH ALZHEIMER'S DISEASE

Because of the progressive, irreversible character of the dementing illnesses of clients enrolled in the demonstration, we do not expect to see substantial changes in their health, cognitive, or functional status. There may be some perceived improvement in the well-being of treatment clients as compared to control clients that are noticed by caregivers. Measures of well-being include physical health, functional capacity, cognitive functioning, emotional well-being, social/interpersonal behavior, and unmet care needs. Because of cognitive impairments, most of these measures will be coded as perceived by the caregiver and will be used as patient outcome measures.

We also expect that differences in the case management intensity available under Models A and B will contribute to differential outcomes for patients being served by the two Models. This effect is likely to be achieved because of the more convenient and intensive training and education of the caregiver that will be available under Model B. We hypothesize the net result of this difference will be better patient outcomes under Model B.

IMPACTS ON SERVICE USE

Because the demonstration represents an expansion of services currently available under the Medicare program, we expect that service use and costs will be higher for the treatment group than the control group. Similarly, because more intensive case management services and higher monthly caps are available under Model B, we expect service utilization and costs to be higher for clients enrolled in this Model as compared with those enrolled in Model A.

The hypothesized effects on overall health expenditures under the demonstration are more ambiguous. Improved case management may lead to reductions in rates of hospitalization because medical problems may be spotted earlier, but any net savings resulting for this type of intervention may be offset by increased rates of institutionalization if this is deemed an appropriate alternative to home care. Specific hypotheses will be tested to assess the effectiveness of different service mix and case management approaches.

IMPACTS ON EXPENDITURES AND EXPENDITURE BURDEN

While it is expected that the demonstration may lead to overall decreases in caregiver burden and increases in utilization of certain currently non-Medicare covered services, comparisons between treatment and control group clients, as well as between treatment group Model A and treatment group Model B, will be required. After adjusting for rates of institutionalization, we expect that total expenditures will be higher for treatment clients than for control clients. Further, we hypothesize that total expenditures will be higher for clients enrolled under Model B than for those enrolled under Model A. We will consider the cost of achieving improvements in client and/or family well-being for the treatment group as compared with the control group. Similarly, we will assess the cost of achieving improvements in selected outcomes by comparing Models A and B.

We also hypothesize that payments for services will be increased for Medicare when comparing the control and treatment groups. However, out-of-pocket expenditures for the client/family may not decrease when comparing the treatment group with the control group. Total out-of-pocket expenditures may actually increase for treatment group participants when compared with control group participants in that treatment group participants, because they have access to services at the rate of a 20 percent co-payment, may actually obtain more services because of this price structure than control group participants who may elect not to obtain the service. In this scenario we would expect more positive impacts for the treatment group, but not necessarily fewer out-of-pocket expenditures when compared to the control group.

Under the terms of the demonstration, case managers are to utilize services covered by other payers (e.g., Medicaid) prior to using demonstration resources. As such, we hypothesize that payments for services from other payers will be unchanged. It is expected that the expanded Medicare coverage will reduce family financial burden, but not with a substitution of Medicare payments for services available from other sources. Family members are allowed, however, to increase the amount of services they were receiving prior to demonstration enrollment. These expanded services can be appropriately reimbursed by Medicare.

Chapter Four

THE EVALUATION

An experimental study design was implemented to test the impact of the Medicare Alzheimer's Disease Demonstration. A total of 6,040 clients were randomly assigned to the treatment (n = 3079) or control (n = 2961) groups. Six sources of data are used to measure the impacts of the demonstration. The data sources include:

- Family application and physician forms for each applicant.
- Baseline intake interview for all treatment and control members and their primary caregivers.
- A 6, 12, 18 and 24-month follow-up interview with the caregivers of members of the treatment and control groups.
- Medicare claims data to obtain information on service utilization and expenditures for the treatment and control groups.
- Claims records submitted to HCFA from the sites to obtain information on the utilization and expenditures for services provided to the treatment group under the Medicare waivers.
- Administrative reporting to HCFA covering demonstration costs, site activities, staffing changes, etc.
- In-person discussions during the site visits with key individuals affiliated with the demonstration in order to obtain qualitative and quantitative assessments of program operations, start-up and implementation issues, and lessons learned from the demonstration.

Baseline data collection began December 1, 1989, and clients continued to enroll in the study sample through April 30, 1991. Each client will be followed for up to 24 months with the final follow-up interviews being completed on May 15, 1993. The evaluation instruments, key variables, and data collection procedures are summarized below.

DATA COLLECTION INSTRUMENTS AND PROCEDURES

Application and Intake Forms

The research design called for the intake interviewers at each site to play a key role in collecting baseline data for both clinical and research purposes. Specially trained and supervised by the evaluators, the intake interviewers were responsible for reviewing completed Family Application Forms and Physician Forms, conducting the baseline Intake Interview and submitting the applicant's name to the evaluators for randomization to the treatment or control group.

Family Application and Physician Forms

At each site the intake interviewer was responsible for obtaining the forms necessary to determine program eligibility. These forms include: the Family Application and Physician Form.

The Family Application Form obtained information on the client's address, telephone number, social security number, Medicare number, Medicaid status and number, current living arrangements, client's demographic characteristics, client's informal caregivers, client's primary care physician, legal guardian, and responsible family members. The Physician Form requested data from the applicant's primary care physician on the patient's type of dementia diagnosis and other medical conditions. When the forms were received, the intake interviewer reviewed them for completeness and made a determination of program eligibility.

To be eligible for the demonstration an applicant had to meet four eligibility criteria: reside within the site's geographic catchment area, have a physician's diagnosis of irreversible dementia, have case management, and/or service needs due to cognitive impairment or functional disability, and be covered by Medicare Part A and Part B.

Baseline Intake Interview

If the applicant met the four demonstration eligibility criteria, a baseline interview was conducted by an intake interviewer with the applicant's primary informal caregiver or a formal paid provider if the applicant had no informal supports. An MMSE was also conducted with each client.

The baseline Intake Interview gathered data in 21 domains:

- Client's demographic characteristics
- Client's beneficiary status
- Client's living arrangements
- Client's physical health
- Client's cognitive and functional impairment
- Client's mental status
- Client's unmet needs
- Client's informal supports
- Client's utilization of formal services
- Caregiver's demographic characteristics
- Caregiver's living arrangements
- Caregiver's employment

- Caregiver's physical health
- Caregiver provision of informal care
- Caregiver's assessment of client's dementia
- Caregiver's assessment of client's behavioral problems
- Caregiver effects of caregiving
- Caregiver's depression
- Caregiver's functional impairment
- Caregiver's use of support services.

As part of the intake process, the intake interviewers were responsible for providing applicants with a written packet of materials about the demonstration, the randomization process, and the use of data obtained from the study. A signed Informed Consent Form was also obtained during the initial in-home interview.

After the baseline Intake Interview was completed, the applicant's name was submitted to the evaluators for randomization. The original Intake Interview was sent to the evaluators for review and data processing. For applicants who were randomized into the treatment group, a copy of the Intake Interview was given to the demonstration site case management staff who incorporated much of the information into the baseline clinical assessment the case managers conducted to determine clients' service needs and develop care plans.

Random Assignment

The procedures for random assignment were straightforward. The intake interviewer filled out a Randomization Form specifying key identifying characteristics of each applicant from information available on the Family Application and Intake Forms. Then, at a predetermined time each week, one intake interviewer from each demonstration site contacted the evaluator and verbally transmitted the data required on the Randomization Forms to a member of the evaluation team. The evaluation team member simultaneously entered the data into a computerized randomization program that immediately assigned each applicant to either the treatment or control group. The randomization algorithm was designed to ensure that intake staff could not "game" the system and to ensure an overall balance between the number of cases assigned to treatment and control.

Follow-up Caregiver Interviews

The primary informal caregiver of each treatment and control group member was interviewed by telephone at 6, 12, 18 and 24 month intervals after date of entry to the study. The evaluators hired and trained as research interviewers nurses and social workers in each of the local communities. Each interviewer was given an assigned caseload to follow throughout the study period. The follow-up caregiver interview covered each of the 21 domains included in the baseline interview as well as a series of questions to measure caregiver satisfaction with services received by the client.

Medicare Records

Medicare claims data is the source of information on the use and reimbursement of services covered by Medicare. Services normally covered under Medicare Part A include hospital stays for acute care and post-hospital extended care services, such as stays at skilled nursing facilities and service provided by home health agencies. Medicare Part B services include visits to physicians and ambulatory facilities, as well as physical and occupational therapy, speech pathology, laboratory and radiology services, and the purchase of durable medical equipment.

Demonstration Claims Data

In order to determine total cost of waivered demonstration services for the treatment clients, each site submitted claims forms to HCFA, which served as the fiscal intermediary for the demonstration services. HCFA developed an automated claims processing system to provide the evaluators with data tapes containing individual identifiers and all service utilization and Medicare reimbursements under the demonstration.

Administrative Reporting to HCFA

Sites were responsible for two main types of administrative reporting to HCFA. Each site prepares a monthly report highlighting site activities, staffing changes, and other relevant information. Each site also submits cost reports on administration, intake, case management and training costs. These reports are used by the evaluation team as a source of data for the process evaluation (discussed below).

Process Analysis

The goal of the process analysis is to provide an understanding of the manner in which the demonstration was actually implemented and of the processes and relationships through which it functions. The analysis examines whether the demonstration and evaluation designs were carried out as planned, whether the characteristics of the clients and site environments affected the outcomes of the demonstration, and the lessons learned from running the demonstration and their implications for implementing similar programs in the future. Chapter six of this report describes each of the eight demonstration sites' key variables that may impact demonstration outcomes.

Summary of Data Collection Protocols and Key Variables

Figure 4-1 lists the data collection protocols and delineates primary data collection responsibility between the demonstration site and the evaluator. Figure 4-2 lists the major study domains and variables for the evaluation and indicates the data source.

Figure 4-1

Summary of Data Collection Protocols and Primary Responsibility for Data Collection

Protocol	Data Collection
Family Application Form	Demonstration
Physician Form	Demonstration
Informed Consent Form	Demonstration
Random Assignment Form	Demonstration and Evaluator
Baseline Intake Interview	Demonstration
6, 12, 18, and 24-month Caregiver Follow-up Interview	Evaluator
Medicare Claims Data	Evaluator
Demonstration Claims Data	Demonstration
Adminstrative Reporting Forms To HCFA	Demonstration
Process Evaluation Data	Evaluator

Figure 4-2
DATA ELEMENTS AND MEASUREMENT PROTOCOLS

	Form/Instrument			
	Family Application Form	Physician Form	Baseline Intake Form	6, 12, 18, and 24-month Follow-Up
PATIENT DATA				
Demographics				
Age, Date of Birth	X			
Gender	X			
Marital Status	X			
Education			X	
Ethnicity			X	
Primary Language	X			
Legal Guardian	X			
Income			X	
Home Ownership				
Beneficiary Status				
Medicare Coverige	X		X	
Medicaid, date eligible			X	X
HMO			X	X
Other Health Insurance			X	X
Living Arrangements				
Household Composition			X	X
Type of Residence			X	X
Length of Time in Current Residence			X	X
Physical Health				
Diagnosis of Dementia		X		
Other Medical Conditions		X		
Cognitive/Functional Status				
MMSE			X	
ADL Impairment			X	X
IADL Impairment			X	X
Reasons for ADL/IADL Impairment (cognitive, physical or both)			X	X
Relationship of Informal Caregivers			X	X
Unmet Need with ADL/IADL Tasks			X	X
Utilization of Services				
Hospital			X	X
Nursing Home (SNF & ICF)			X	X
Board & Care/ACLF/Residential Care			X	X
Other Supportive Housing			X	X
Physician Visits			X	X
Medical Specialists Visits			X	X

	Family Application Form	Physician Form	Baseline Intake Form	6, 12, 18, and 24-month Follow-Up
Mental Health Services			X	X
Dental Services			X	X
Adult Day Health/Social Day Care			X	X
In-home Respite Care			X	X
Congregate Meals			X	X
Home Delivered Meals			X	X
Nursing Service			X	X
Physical/Occupational/Speech Therapy			X	X
Home Health Aide			X	X
Homemaker/Housekeeping			X	X
Live-in Caregiver			X	X
Companion Services			X	X
Client Education Training			X	X
Client Support Group			X	X
Transportation			X	X
Adaptive & Assistive Equipment			X	X
Medical Supplies/Equipment			X	X
Consumable Care Goods			X	X
Home Modifications			X	X
Medications			X	X
Adult Protective Services			X	X
Case Management Services				
Number of Contacts			X	X
Type of Assistance			X	X
Unmet Service Needs			X	X
Services Not Used Due to Co-Pay				X
Service Satisfaction				
Social Day Care/Adult Day Health Care				X
Out of Home Respite Care				X
Personal Care Services				X
Homemaker/Housekeeping				X
Companion Services				X
Case Management				X
Reasons Services Not Utilized				
Social Day Care/Adult Day Health Care				X
Out of Home Respite Care				X
Personal Care Services				X
Homemaker/Housekeeping				X
Companion				X
Case Management				X

	Family Application Form	Physician Form	Baseline Intake Form	6, 12, 18, and 24-month Follow-Up
CAREGIVER				
Demographics				
Age			X	
Marital Status			X	
Education			X	
Income			X	
Health Care Coverage			X	X
Physical Health				
Subjective Assessment of General Health			X	X
ADL/IADL Limitations			X	X
Employment				
Current Hours Employed			X	X
Restrictions Due to Caregiving			X	X
Caregiving				
Length of time Caregiver				X
Hours spent caregiving			X	X
Level of Supervision Client Requires			X	X
Caregiver Assessment of Client's Dementia			X	X
Caregiver's Assessment of Client's Behavioral Problems			X	X
Effects of Caregiving				
Caregiver Stress & Burden			X	X
Caregiver Depression			X	X
Use of Caregiver Support Services				
Mental Health Services			X	X
Education/training			X	X
Support Group			X	X
Legal/Financial Counseling			X	X
Unmet Need for Services			X	X

THE STUDY SAMPLE

Table 4-1 shows the number and proportion of clients randomized into the treatment and control groups at baseline. In the Model A sites, the 2,830 clients were evenly distributed among the four sites: Illinois (25.7 percent); New York (23.7 percent); Oregon (25.5 percent); and Tennessee (25.0 percent). Within each site the clients were almost equally divided between the treatment and control groups with less than one percent difference in the proportion of clients in the experimental and control groups at each site. In the Model B sites there was some variation in the distribution of the 3,079 total clients: Florida (28.5 percent); Minnesota (33.6 percent - representing the largest site); Ohio (24.0 percent); and West Virginia, (13.8 percent - representing the smallest site). Within each site, the proportion of treatment and control group members were evenly distributed. Overall, 51 percent of the study sample was in the treatment group and 49 percent was in the control group. Model B sites had slightly more clients (53 percent) than Model A sites (47 percent).

SAMPLE ATTRITION AT THE 6-MONTH FOLLOW-UP

The data in Table 4-2 show the number and proportion of sample members who attritted from the study between the baseline intake interview and the 6-month follow-up interview. Overall, sample attrition during the first six months of the study was slightly higher in Model B (11.2 percent) than Model A sites (8.9 percent). For both models the two primary reasons for attrition were death (5.5 percent in each model) and permanent institutionalization (2.6 percent in Model B and 1.3 percent in Model A). Less than 2 percent of clients attrited for other reasons (e.g., moved out of catchment area, lost to follow-up, refusal).

In the Model B sites, there was slightly more attrition in the control group (11.7 percent) than in the treatment group (10.8 percent) primarily due to higher proportions of control clients who died. In the Model A sites there was almost no difference in client attrition at six months (treatment group 9.0 percent, control group 8.8 percent).

In both models, a slightly larger proportion of the treatment group members became permanently institutionalized during the first six months of the study, while a slightly larger proportion of the control group died. Table 4.3 provides more detailed information on sample attrition by site and group. While there was some variation between sites, there were no marked differences.

TABLE 4-1

THE STUDY SAMPLE
TREATMENT & CONTROL GROUPS, BY MODEL, BY SITE

Group & Site	Treatment (n=1438)		Control (n=1392)		Total (n=2830)	
	N	%	N	%	N	%
Model A						
Illinois	370	25.7	364	26.1	734	25.9
New York	341	23.7	329	23.6	670	23.7
Oregon	367	25.5	357	25.6	724	25.6
Tennessee	360	25.0	342	24.7	702	24.8

Group & Site	Treatment (n=1641)		Control (n=1569)		Total (n=3210)	
	N	%	N	%	N	%
Model B						
Florida	469	28.5	454	28.9	923	28.8
Minnesota	551	33.6	511	32.6	1062	32.1
Ohio	394	24.0	366	23.3	760	23.7
West Virginia	227	13.8	238	15.2	465	14.5

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 4-2

SAMPLE ATTRITION AT 6-MONTH FOLLOW-UP TREATMENT & CONTROL GROUPS, BY MODEL

Group & Reason for Attrition	Treatment (n=1438)		Control (n=1392)		Total (n=2830)	
Model A	N	%	N	%	N	%
Institutionalized 1	24	1.7	14	1.0	38	1.3
Deceased	78	5.4	78	5.6	156	5.5
Moved out of area	16	1.1	11	0.8	27	0.9
Ineligible diagnosis	0		0		0	
Unable to locate	0		7	0.5	7	0.2
Refused	8	0.5	11	0.8	19	1.6
Other 1	4	0.3	2	0.1	6	0.2
TOTAL ATTRITION	130	9.0	123	8.8	253	8.9

Group & Reason for Attrition	Treatment (n=1641)		Control (n=1569)		Total (n=3210)	
Model B	N	%	N	%	N	%
Institutionalized 1	54	3.2	29	1.8	83	2.6
Deceased	71	4.3	108	6.9	179	5.5
Moved out of area	30	1.8	16	1.0	46	1.4
Ineligible diagnosis	0		0		0	
Unable to locate	1	0.1	2	0.1	3	0.1
Refused	17	1.0	21	1.3	38	1.1
Other 1	5	0.3	7	0.4	12	0.3
TOTAL ATTRITION	178	10.8	183	11.7	361	11.2

SOURCE: UCSF/Instit. for Health & Aging. HCFA-Alzheimer's Disease Evaluation. 1992

[1] Clients who were permanently institionalized were followed for a 12-month interval as a special sub-sample. Includes primarily clients who should not have been admitted to the study because they were already receiving similar services from another provider.

TABLE 4-3

SAMPLE ATTRITION AT 6-MONTH FOLLOW-UP
TREATMENT & CONTROL GROUPS, BY SITE, BY MODEL

Group & Reason for Attrition	Illinois				Tennessee				Oregon				New York			
	Treatment (N=370)		Control (N=364)		Treatment (N=360)		Control (N=342)		Treatment (n=367)		Control (n=357)		Treatment (n=341)		Control (n=329)	
Model A	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Institutionalized[1]	8	2.2	2	0.5	1	0.3	2	0.5	3	0.8	2	0.6	12	3.5	8	2.4
Deceased	20	5.4	15	4.1	10	2.8	25	7.3	31	8.4	22	6.2	17	5.0	16	4.9
Moved out of area	5	1.3	2	0.5	3	0.8	2	0.5	8	2.2	5	1.4	0		2	0.6
Ineligible diagnosis	0		0		0		0		0		0		0		0	
Unable to locate	0		1	0.3	0		0		0		2	0.6	0		4	1.2
Refused	2	0.5	0		2	0.5	5	1.4	1	0.3	2	0.6	3	0.9	4	1.2
Other	1	0.3	0		0		1	0.2	3	0.8	2	0.6	0		0	
TOTAL ATTRITION	36	9.7	20	5.5	16	4.4	34	9.9	46	12.5	35	9.8	32	9.4	34	10.3

Group & Reason for Attrition	Florida				West Virginia				Ohio				Minnesota			
	Treatment (N=469)		Control (N=454)		Treatment (N=229)		Control (N=237)		Treatment (n=394)		Control (n=366)		Treatment (n=551)		Control (n=511)	
Model B	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Institutionalized[1]	12	2.6	8	1.7	10	4.4	2	0.8	17	4.3	8	2.2	15	2.7	11	2.1
Deceased	29	6.2	34	7.5	9	3.9	16	6.7	15	3.8	37	10.1	18	3.3	21	4.1
Moved out of area	18	3.8	9	2.0	6	2.6	0		2	0.5	4	1.0	4	0.7	3	0.6
Ineligible diagnosis	0		0		0		0		0		0		0		0	
Unable to locate	0		1	0.2	0		2	0.8	0		0		0		0	
Refused	10	2.1	11	2.4	0		1	0.4	4	1.0	4	1.1	3	0.5	5	1.0
Other	2	0.4	0		2	0.9	5	2.1	0		1	0.3	1	0.1	1	0.1
TOTAL ATTRITION	71	15.1	63	13.9	27	11.8	26	11.0	38	9.6	54	14.7	41	7.4	42	8.2

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

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[1] Patients who were permanently institutionalized were followed for a 12-month interval as a special sub-sample. Includes primary patients who should not have been admitted to the study because they were recieving similar services from another provider.

Chapter Five

IMPLEMENTATION ISSUES: PROGRAM DESIGN AND EVALUATION

An experimental research design was selected for the demonstration wherein participants are randomly assigned to either control or treatment groups. Under this design, treatment group participants receive demonstration services while control group participants receive only services that would be normally available in their communities. In order to be included in the program, demonstration sites agreed to cooperate in randomization and data collection activities. Demonstration sites were also required to develop community outreach efforts necessary to enroll the appropriate number of Medicare beneficiaries for the successful evaluation of the project.

To implement the demonstration in the context of the evaluation design, a number of decisions were made that provided guidelines to the sites for operationalizing the models being tested. Implementation issues arose in client outreach/eligibility, case management staffing patterns, minimum case management data and basic client assessment areas, client changes in status, and attrition replacement. These issues are addressed separately below.

CLIENT OUTREACH AND ELIGIBILITY

To mitigate against contamination of the evaluation design that may occur as a result of procedures necessary to enroll clients into the demonstration, a number of policies were developed to provide site staff with guidelines for enrolling clients. "Contamination" in the context of the demonstration refers to the receipt of services equivalent to those offered through the demonstration. Receipt of such services by the control group would seriously affect the evaluation in that, for all practical purposes, there would be no difference between the services received by the treatment and control groups.

Service Intervention by Intake Interviewers During Enrollment

Client safety, both at the time of the evaluation intake interview and after enrollment into the demonstration, was an important concern of HCFA, the demonstration sites, and the evaluation team. Guidelines were developed in conjunction with HCFA and the sites to insure that client needs in this area were not secondary to the implementation of the demonstration or the evaluation design. Life threatening or other emergency interventions (e.g., elder abuse, protective service, or institutionalization actions) necessary during initial contacts with the client or their families were responded to as appropriate. Any client who required interventions because of safety concerns prior to randomization was deemed ineligible to participate in the demonstration.

The policy that was promulgated regarding interventions in such cases was that emergency or life threatening situations arising after randomization into the treatment group received whatever assistance was appropriate by either the host demonstration site or through referrals to other agencies. Among the control group, it was possible that referrals for assistance would come through the demonstration host agency and sites were instructed to respond to these requests in their standard practice manner, not using the services of the demonstration or the demonstration case managers.

If, during the intake interview, the interviewer provided assistance to the client or caregiver (e.g., the interviewer assisted the caregiver in cleaning the client after an episode of incontinence), but there was no discussion of where to go for help with the problem and no referrals were made for further outside assistance, then the client remained eligible for participation. If the client or caregiver requested a referral for help, a standardized handout listing the name of the two referral sources identified by the site (i.e., an information and referral agency and the local Alzheimer's Association) was given to them by the interviewer. If in the course of providing assistance to the client or caregiver during the intake interview the interviewer found it necessary to provide information about other service providers in the community beyond that contained in the standardized handout, then the person was no longer eligible for the demonstration.

If an accident or a problem arose during the intake interview that was not an emergency but needed to be resolved before the interview could be completed, the following options were available for the intake interviewer:

- Interviewers could suggest that they would be happy to wait while the caregiver and client take care of the problem; or
- Interviewers could reschedule a time to return and complete the interview.

The critical factor in the intake interviewer's determination of whether an applicant remained eligible for the demonstration was the provision of information about service providers in the community beyond that available on the standardized handout. If any information beyond the standardized referral handout was provided, then the client was ineligible for the demonstration.

Interviewers were instructed to treat information requests for services received before or after a client was assigned into the control group in a uniform manner. All responses to such requests took the form of the standardized handout listing the names of the two identified referral sources. If information requests were directed to the site from any agency or potential applicant, they were responded to in the site's standard practice manner and did not involve the demonstration case managers. If an applicant exhibited or expressed non-emergency service needs during intake but did not request help, the interviewer did not volunteer referral information. This was a necessary procedure to reduce control group contamination. Sites were also instructed that, if after randomization a control group member/caregiver called the site, the client or caregiver should be treated in the site's standard manner but they remained ineligible for any demonstration services.

Determination of Clients' Unmet Needs

The eligibility criteria for the demonstration specified that clients had to have "unmet needs" to be considered for participation in the demonstration. For the sake of operational simplicity, if the client/caregiver applied to the demonstration and the client's physician completed and returned a physician referral form to the site, these were actions which, in and of themselves, constituted "unmet need" for the demonstration services. With the exception of "rollover" cases defined below, clients were allowed to enroll in the demonstration regardless of the type or level of current formal or informal services. Implicit in this interpretation was the decision that the treatment group did not have to be segregated from the controls if they were receiving non-demonstration services.

Guidelines for Classifying Clients on "Roll-Over" Cases

The concern with "rollover" cases was how to minimize the possible contamination of the control group. "Rollover" cases consisted of: 1) clients who wanted to participate in the demonstration but who potentially were receiving services that equalled or surpassed those that could be obtained from the demonstration if they were randomized into the control group; and 2) clients who did not have either an informal or formal caregiver. Communities with 2176 Medicaid waiver programs were the most frequent source of rollover clients. The 2176 Medicaid Waiver programs provide expanded community-based services to Medicaid eligibles. The services covered under this program vary by state. Efforts to minimize contamination began with the consideration of the question: "What is the purpose of the demonstration, to compare the effectiveness of the case management and waivered reimbursement for services against no case management and no reimbursement for services; or to compare the benefit of the demonstration's reimbursement and case management against the prevailing treatment experience in the community?" Since the latter purpose was deemed appropriate, and sites had no ability to control what happened to the control group or in the community service delivery system, the most effective point in time for minimizing contamination was at enrollment into the study.

To minimize contamination, each site identified programs in their community which were offering case management services comparable to, or more extensive than, those offered by the demonstration. Such programs included Medicaid waiver programs, other federal demonstrations, or certain specialized housing projects such as life care. Residential care housing did not automatically fall into this category. Sites were given the option to categorically exclude from the demonstration everyone receiving services from these types of programs.

For sites that chose not to categorically exclude persons receiving services from programs similar to the demonstration intervention, the site could enroll a maximum number of clients from all of these programs taken together. For sites that chose this option, the total number of allowable rollover clients in both treatment and control groups was computed based on the total number of "non-rollovers" necessary to statistically detect the effects of the demonstration.

Because it was anticipated that many clients and their caregivers would not know that they were receiving case management services, since the term may be unfamiliar to them, sites were provided a script with appropriate probes so that the determination of a rollover client could reasonably be made. If an applicant was receiving services from a "rollover" program identified by the site, site staff were instructed to call the agency to determine what services were being received by the applicant. If the applicant was receiving case management services similar to the demonstration intervention, then they would be considered a rollover for purposes of the rollover caps established for each site. The judgement as to "potentially" duplicative service providers was left to the case managers at each site because of their detailed knowledge of the structure of services provided in their community.

Within the months of December, January, and February 1989-90, one out of three cases submitted for randomization were allowed to be rollovers, up to a site's maximum number of allowed rollovers. If an applicant was receiving services from one of these identified agencies, site staff called the agency to determine what services were being received by the applicant. If the applicant received case management services similar to the demonstration intervention, then they were considered a rollover for purposes of the rollover caps that were established for each site.

If sites did not reach their rollover caps in the first 3 months of the enrollment period, they continued to randomize rollovers into the demonstration until the caps were reached. If a rollover client left the demonstration for any reason (e.g., death, moved out of the area) after the cap was reached, the client had to be replaced with a non-rollover case. During the course of, and after the completion of, the demonstration enrollment period, evaluation staff checked on rollover cases to confirm whether they were actually rollover cases. Staff used the following criteria to assess whether a case was a legitimate rollover:

- the case had to be open to case management at the time of the demonstration intake interview;
- The case management being received had to be more than just establishing ongoing eligibility; it must be long-term; and the frequency and intensity of contact must be enough that the client (or more likely, the caregiver) knows the name of the case manager and the case manager would likely be in contact with the client (or caregiver) when assistance was needed;

A small percentage were found not to be rollovers and were taken out of that category for purposes of characterizing the enrolled sample. The rollover caps were established to ensure an adequate number of non-contaminated cases at each site. The goal was to enroll no more than 15 percent of the study sample. As the data in Table 5-1 show, no site reached its maximum number of allowable rollover cases.

Diagnosis of Dementia

Clients were deemed eligible for the demonstration if their physician-attested to the fact that the client had an irreversible dementia. A requirement to obtain a differential diagnosis of dementia as a condition for participation was considered but was deemed to be problematic both in terms of time and cost. With regard to cost, for example, if all of the approximately 6,000 people enrolled in the demonstration were given a comprehensive diagnostic work-up to determine eligibility, the cost would have been approximately $6 million or 15 percent of the original congressional appropriation for the entire service portion of the demonstration (assuming a conservative cost of $1,000 per client per work-up). Time limitations also would have made it impossible to complete diagnostic work-ups on all clients. For example, across California's nine specialized Alzheimer's Disease Diagnostic and Treatment Centers (ADDTCs) an average of 900 patients are assessed per year. Even if clinical facilities located in the communities of the eight sites could complete three times as many diagnostic work-ups per year than ADDTCs (i.e., 2,700 clients evaluated across all sites per year), it would still have taken over two years just to diagnose everyone enrolled in the demonstration. This length of time does not include finding cases. Because of these constraining factors, HCFA and the evaluators chose to rely on the patient's physician's judgments. At their request, sites were provided with the following guidelines for a diagnostic work-up to distinguish a reversible from an irreversible dementia. The required steps (estimated to cost between $1,500 and $2,000) to make this differentiation were as follows:

- A comprehensive history and physical
- Mental status examinations including tests such as the MMSE, a verbal fluency test, and the Blessed Orientation Concentration Test
- A DSM-III criteria checklist for depressive symptomatology such as is available on the Diagnostic Interview Schedule
- A comprehensive neurological examination
- A complete blood screen including B12 and VDRL
- An imaging procedure such as a Computerized Axial Tomography scan to detect treatable silent brain tumors or reversible hydrocephalus.

TABLE 5-1

CASES WITH POSSIBLE DUPLICATE CASE MANAGEMENT PROVIDER BY MODEL AND SITE

Group & Site	Total Enrolled[a]	# Receiving Case Management at Time of Enrollment	% Enrollment
Model A			
Illinois	734	96	13.1
New York	670	34	5.1
Oregon	724	86	11.9
Tennessee	702	43	6.1
Subtotal	2830	259	9.2

Group & Site	Total Enrolled	# Receiving Case Management at Time of Enrollment	% Enrollment
Model B			
Florida	923	106	11.5
Minnesota	1062	143	13.5
Ohio	760	101	13.3
West Virginia	566	30	5.3
Subtotal	3311	380	11.5
Grand Total	6141	639	10.4

SOURCE: UCSF/Instit. for Health & Aging. HCFA-Alzheimer's Disease Evaluation, 1992

[a] Includes all cases ever enrolled into either treatment or control group within each site. The proportion is approximately equal in both groups.

During the implementation of the demonstration, a question arose from the sites regarding how a diagnosis of "non-specific" dementia should be handled in determining eligibility for the demonstration. Since a major consideration in evaluating the eligibility of an applicant was whether the referring physician had concluded that the client had an irreversible dementia, it was not essential that they classify the dementia into the various eligible diagnoses provided to them as part of the physician's referral form. Questions also arose about situations where a patient has, for example, an Alzheimer's disease diagnosis (an eligible disorder) in conjunction with alcoholic dementia (an ineligible disorder). The policy was that as long as an irreversible dementia diagnosis is included in the physician's assessment, the client is eligible to participate in the demonstration. If a client is later found to have a reversible dementia during the course of the demonstration, the client would be terminated from the study and replaced in the sample.

Changes in Client Status

A number of guidelines were developed to provide information to sites regarding how to handle clients who change status (e.g., death, institutionalization) during the demonstration. Figure 5-1 outlines the follow-up procedures for treatment group clients who had a change of status during the demonstration. This table addresses a broad range of follow-up procedures for clients who had a status change during the course of the demonstration. Included in the table are procedures for treatment group clients who either die, enter a hospital or nursing home, are found to have a reversible dementia, do not pay the coinsurance, fail to comply with demonstration services, etc.

Use of Demonstration Clients in Other Research

The use of demonstration study subjects in other research projects was guided by the following policies: 1) the evaluation data will not be released until the end of the evaluation and then only with HCFA approval; 2) sites can use their own assessment data or other data as long as the use of these data were non-obtrusive to the clients; and 3) no outside research be initiated that might impact on the time, energy or cooperation of the study subjects or their family members.

COMPLIANCE WITH THE CASE MANAGEMENT MODELS

A major staffing issue arose in the implementation of the evaluation: how to model a full complement of clients for case managers during the client build-up phase. Since client-to-case manager ratios are an important aspect of the demonstration, a method to model full caseload during the period of time it took to achieve full caseload was developed.

The role of case aides and other clerical support to the case managers was a confusing aspect of the demonstration in terms of the delineation of appropriate professional and support roles. Because of the importance of achieving as consistent an implementation of the case management models across sites as possible, sites were provided guidelines to help them delineate the total staff effort allocated for support to the professional roles in case management. Without consistency, there would have been the potential for contamination of the demonstration from the standpoint of the case manager-to-client ratios. The guidelines that were developed included the following case manager roles:

- Case assessment
- Care plan development
- Problem solving and service quality monitoring with the providers
- Problem solving and care plan implementation with the family
- Training of caregivers
- Specifying which referrals are appropriate for the Case Aide to arrange

Counseling services with the patient or family members were expressly excluded as a case management responsibility. These were considered separate services. All other general advice and family support were acceptable case management activities.

To insure the integrity of the models, guidelines were developed for calculating the total amount of case management time that, on average, should be expended per client each month during the client enrollment phase. The time limitations for case managers that were developed for both models were based on a number of straightforward assumptions. First, case managers in Model A sites would have 100 clients at full enrollment while Model B case managers would have 30 clients. Second, case managers under both models would work an average of 40 hours per week. The time guidelines were based on a calculation of the average amount of time per client a case manager would expend at full enrollment under each model. Case manager activities that were not included as part of the time limitations were:

- outreach activities for purposes of caseload build-up
- administrative or other tasks that were not concerned with case management, but that were done so as not to exceed the average case manager-to-client time limitations established for purposes of modeling a "steady-state" program
- client assessment activities up to the point where the case manager reaches 50 percent of full caseload
- activities engaged in by case managers that are a separate billable service.

Figure 5-1

Follow-Up Procedure for Clients Who Change Status

Status Categories	Continue Management Services?	Include in Case Management to Client Ratio Calculation?	Continue Providing Direct Services?	Replace in Sample
Death	Continue for 60 days following client's death	For 60 days following client's death	For 60 days following client's death, at site's discretion	Yes, if death occurs before October 1, 1990
Short-term hospital or nursing home stay	Yes	Yes	Generally no, except for special exceptions (e.g., continue attending adult day care if nursing home stay is for respite care)	No
Long-term institutionalization	Continue for 60 days following institutionalization	For 60 days following institutionalization only	No	Yes, if long-term institutionalization occurs before October 1, 1990
Determination that client has reversible dementia	Continue for transition period while directing patient to alternative services, no longer than two months	For transition period only, no longer than two months	For transition period only, no longer than two months	Yes, if new diagnosis is obtained before October 1, 1990
Non-payment of co-insurance for services	At discretion of sites	No; if case management continues, yes	At discretion of sites	No, if case management and/or services continue. Yes, only if case management and direct services discontinue
Client/caregiver disenrollment	No	No	No	Yes, if disenrollment occurs before October 1, 1990
Family elects to not utilize services	Yes	Yes	No	No

Note: If primary caregiver dies or is permanently institutionalized, identify a new primary caregiver for the 6-month follow-up and report the information to Institute for Health & Aging.

In the Miami site, the case management model utilizes a unit with five Care Coordinators and one RN Consultant. The Care Coordinators maintain an active caseload and the RN consultant has specific responsibilities (assessment, care planning consultation and patient education) for all patients in the unit. The Miami site client to case manager ratio was 1:30, but case managers had caseloads of 36, and the RN worked with all the case managers caseloads to achieve the 1:30 ratio. The time of the RN Consultant was considered as case manager time although spread across a larger number of clients.

A 5 percent variance above or below the target client-to-case manager ratios was also set. For Model A sites the average variance per case manager at full enrollment using the guidelines is between 95 and 105 cases. For Model B sites the variance ranges from 28 to 32 clients per case manager at full enrollment. To monitor the client-to-case manager ratios at each site, sites submit a monthly report that includes data on the average number of clients per case manager per day. This average number is calculated by adding the per-day case manager caseload by the number of working days in the month (including holidays, vacation and sick leave).

Since a major goal of the evaluation is to understand how the models would operate if they were part of a regular Medicare benefit, measures of client and caregiver outcomes in relation to each intervention necessitated that the programs attempt to operate in as close to "steady-state" as possible. The rationale for setting the time targets was for sites to begin operating as if at full enrollment as early in the demonstration as possible. If this was ignored, then the effects of the two models on the entire caseload would be difficult to assess because clients enrolled early in the demonstration would be receiving case management services under a lower case manager-to-client ratio than those enrolled later in the demonstration. The degree to which site case managers conformed to these guidelines is discussed in Chapter Six.

The average time-per-client constraints that were set were most difficult for the Model A case managers. The extremely limited amount of time case managers had available to deal with client and caregiver problems was a major service delivery constraint for the sites. In the 1:100 model, case managers were instructed to spend an average of 1.5 hours per active case per month. In the 1:30 model, case managers were instructed to spend an average of 5.3 hours per active case per month. These guidelines did not mean that case managers had to spend 1.5 hours (Model A) or 5.3 hours (Model B) on each client per month. Some clients required very little time while others required significant amounts. The goal was for case managers to spend no more than a total of 1.5 hours (Model A) or 5.3 hours (Model B) per enrolled client per month in case management activities.

The constant ratio of case managers to clients was an attempt to maintain the case manager-to-client ratios in both models. As caseloads grew, the total amount of time spent in case management activities increased until case managers were fully occupied in their professional roles. Until full caseload was reached, case managers were instructed to devote their time to other important non-case management activities, such as outreach, to enroll clients.

Guidelines were also developed for case aides which were used in the Model A sites. Sites were instructed to have one FTE case aide to provide case managers with assistance for each 150 clients enrolled at a site. A constant ratio of case aide to clients was developed to facilitate the effectiveness of the planned ratio of case managers to clients in both the Model A and Model B sites. The average case aide-to-client ratio was 30 minutes per case per week. As was the case with case managers, this did not mean that case aides had to spend 30 minutes on each client per week. Some clients require very little time while others require significant amounts. The goal was for case aides to spend no more than a total of 30 minutes per enrolled client per week in case management support activities. This limitation only referred to the time a case aide spends assisting the case manager. Case aides could do other types of activities if there were more case aides hired at a site than the 1:150 case manager-to-clients ratio.

Case aides were not required for Model B sites. With their lower client-to-case manager ratios, Model B site case managers did not necessarily need additional help from case aides. Unlike Model A sites with a much higher caseload, Model B site case managers are able to spend a significantly greater proportion of their time working with their clients. In Model B sites located in service resource rich areas, case managers were concerned that too many professionals would be visiting, thereby potentially increasing stress on the caregiver. Because of this, the case aide time guidelines that were developed outlined the upper limit for FTE case aides per site. So as to not overly constrict the activities of case managers, each site was responsible for determining whether case aides were needed. If they were used, sites were directed not to exceed the established FTE limits during the client enrollment phase to help insure the integrity of the models until full caseload was reached.

The client enrollment phase represented a significantly different situation than at full caseload given the number of new clients that had to be assessed and processed per month. Because of the need to enroll an entire caseload as quickly as possible to fit into the timeline of the demonstration, sites were instructed to exclude the time required to conduct comprehensive assessments from the average time-per-client allocation guidelines for case managers until a case manager had one-half of their caseload (i.e., 50 clients in Model A and 15 in Model B).

MINIMUM CASE MANAGEMENT DATA AND DELINEATION OF BASIC CLIENT ASSESSMENT

Guidelines were developed for minimum information standards across the major case management assessment domains. Sites were free to add other items of information in order to tailor assessment and care/action plan activities to the needs of clientele.

In addition to the data included on the IHA application, physician referral, intake and HCFA fiscal reporting forms, the list of minimum client assessment/case management data that the sites were instructed to maintain on a client-by-client basis appear below:

- Client ID number
- Client name
- Caregiver name
- Date of randomization
- Date of case management assessment
- Location of case management assessment (e.g., home, office, etc.)
- Date case management initiated
- Client and caregiver reported problems and needs (from the assessment form)
- Case manager's perception of client and caregiver's problems and needs
- Plan of action to address identified problems
- Time frames for the implementation of the action plans
- Goals and objectives of planned interventions
- Service information for clients and caregivers
- Medicare and Medicaid client certification/recertification (date of encounters)
- Standard 6, 12, 18, and 24-month reassessments (date of encounters)
- Supplemental reassessments for clients at less than the standard 6, 12, 18, and 24-month intervals (date of encounters)
- Service monitoring and follow-up including date of encounter; initiator of encounter (i.e., case manager, case aide, caregiver, client, other: specify); reason for encounter (i.e., routine follow-up, provider problem, medical emergency, other: specify); and, whether there was a change in the clients' care plan (i.e., yes or no)
- Training and education activities (specify type and duration of training education

Given the difference between the models in terms of client-to-case manager ratios, the specific data and mode of assessment that case managers used was up to each of the sites. The delineation of basic assessment areas important to consider during a comprehensive case management assessment was developed in consultation with the site directors. The sites were given the responsibility to determine what information was important for their case managers to collect in the broad areas of demographic, support system, home environment, health history, functional, psychiatric/behavioral, legal/protective, and formal service utilization. The evaluation team's concern was that all sites were assessing clients in these broad areas, as these are seen as essential to adequate case management and care planning.

TECHNICAL ASSISTANCE IN IMPLEMENTATION OF THE CASE MANAGEMENT MODELS

As part of the evaluation contract, technical assistance was provided to sites primarily in the area of the implementation of the case management models. Case management for people with Alzheimer's disease is a relatively new professional specialty. As the demonstration began, it was anticipated many sites would not be able to hire staff with training and/or experience in this area. Thus, a plan was made at the outset to contact each of the sites in order to determine if there were any training or informational needs that could not be met on site.

A telephone survey revealed a wide range in the level of need for staff training. Sites also identified training and information needs for caregivers and in-home support staff who would be providing direct services to clients. Some of these unmet training needs were shared across sites. One need many of the sites had in common was a better understanding of the administration and justification for use of certain scales used in the intake instrument - specifically the caregiver stress and burden scale, the depression scale, and the MMSE. Background information on the reliability and validity of these scales, as well as scoring and administration methods, was mailed to all of the sites.

In addition, there were many requests for further information on specific topics. These requests fell into two major categories: a) information regarding Alzheimer's disease symptoms and behaviors and appropriate interventions for handling these; and b) guides and procedures regarding the process of case management. Requests for assistance in this latter category came from all the Model A sites as they began to assess the difficulties of providing case management services to clients with one case manager for every 100 clients. It was concluded from this initial survey that there was an urgent need for a training and technical assistance meeting for the Model A sites.

The training was held on April 10 through April 12, 1990 in Baltimore, Maryland. Prior to the meeting, sites sent samples of their assessment tools to IHA for review. Packets of information were prepared for distribution at the meeting containing a review of community-based long term care experiments to date, some resources for caregivers, an in-house review of basic principles of case management as well as a bibliography of articles that dealt with case management or Alzheimer's disease or both. However, the most important outcome of the meeting was agreement about certain basic domains that had to be covered in some fashion by all case managers during client/caregiver assessment. These included: 1) demographic information; 2) assessment of support systems; 3) environmental assessment; 4) client health history; 5) client functional assessment; 6) behavioral assessment; 7) legal, financial, and protective service issues; and 8) assessment of the use of formal services.

The evaluation team began to receive calls from case managers as the process of randomization began. The majority of these calls were from Model A sites as case managers struggled to define the parameters of a less intensive model of case management, i.e., 1 case manager for 100 clients. Site visits by the training and technical assistance coordinator were conducted to help resolve some of the issues arising at the sites. These visits were completed by May 1990.

Among the many issues discussed at these site visits were: 1) elements that needed to be included in a care plan; 2) the most effective way to make use of nursing staff with expertise in geriatrics; 3) how case managers could provide support for clients and caregivers without finding themselves in a professional "counseling" role; 4) the possibility of using (and how should the project define) "independent contractors" as service providers for the clients; and 5) how to deal with a multi-lingual, multi-ethnic client and service provider mix.

In addition, at each site plans were reviewed for establishing caregiver education, training, and support groups and sites were invited to submit especially difficult or demanding cases for discussion and consultation. The sites also expressed a desire to have a training and technical assistance meeting with all sites represented (rather than by model) only to learn from each other and share problems with (and sometimes successful techniques for) training and retraining in-home providers (usually personal care), attracting caregivers to educational support groups, and managing crises effectively.

The Model B case manager technical assistance meeting was held in Baltimore on June 13, 1990. Again, an informational packet was prepared and distributed at the meeting. Many of the problems uncovered at the site visits were discussed at this time and sites shared their methods of resolving them. Among items discussed were: 1) ways of using leverage to obtain the best services for demonstration clients; 2) identifying barriers to service utilization; 3) alternative ways of training and supporting caregivers; 4) the appropriate use of medical, psychiatric, legal and pharmacological consultants; and 5) defining what was expected by the evaluation team in terms of case documentation.

Another technical assistance meeting for both Model A and Model B sites was held in Baltimore on March 26 and 27, 1991. It was held in response to requests from the sites that new problems were occurring in implementing both models as sites reached full projected enrollment. In addition, as a result of staff turnover, many new case management staff had been hired who had not been on board and able to attend previous training. This meeting covered topics such as: 1) the reasons for underutilization of services by caregivers (especially mental health services), and a discussion of how case managers could attempt to deal with this issue; 2) identifying and dealing with elder abuse and neglect including emotional, physical, and financial abuse; and 3) methods of working with families to avoid unnecessary or premature institutionalization of clients. Many site-specific issues around implementing the model were also covered at this meeting. A packet was prepared with articles and other materials for the sites.

This meeting was followed by a request from the West Virginia and Oregon sites for further assistance. A site visit was made to Wheeling, West Virginia directly following the meeting in Baltimore. One of the main issues dealt with was the appropriateness of the demonstration for treatment of extremely physically ill clients. As the demonstration was "aging," so were many of the original client intakes and the Wheeling site had several caseloads with a high number of clients requiring intense levels of skilled nursing in order to remain at home. The responsibilities as well as the limitations of the demonstration were reviewed. As client needs became more intense and complex, greater responsibilities and the need for excellent clinical judgment were beginning to become a necessity for case managers. Ways to upgrade the skills of current staff were discussed as well as the need for ongoing staff training and effective use of consultants and available educational resources in the area.

Later in the month a site visit was made to Portland, Oregon. Portland had an almost entirely new staff since the inception of the program. Understandably, they had many questions about implementing the 1-to-100 model and the focus of the day was how to inform, support, and empower caregivers as the case manager-to-client caseload ratio reached the 1-to-100 objective. The assessment procedure had been revamped and streamlined and it was re-reviewed by the training and technical assistance coordinator during this site visit in order to determine if the essential assessment domains were still being adequately addressed.

Another aspect of the training and technical assistance portion of the demonstration was random chart reviews that were completed in July 1990. Each site sent in two to four charts, randomly identified by site and client identification numbers, for review. The training and technical assistance coordinator then reviewed the charts as one method of assessing quality assurance during the implementation of the case management models. The following criteria were used to determine if the demonstration minimum case management standards were being met:

- clear definition of the presenting problem
- adequacy and appropriateness of the care plan
- the timeliness of the implementation of the service plan
- evidence in the chart of regular phone and/or in-home care monitoring of service providers

- the effectiveness of the pr m-solving techniques employed
- evidence of a process for d mining if case objectives were being met in a timely fashion
- the organization and completeness of the documentation

The intensity and the time spent on individual cases varied by model type but overall it was clear that all sites were effectively meeting at least minimum, and at best very high, standards for case management with this extremely challenging and difficult group of clients. Written feedback on each chart submitted for review was supplied to all sites in a 25-page document prepared by the training and technical assistance coordinator. The quality of case management intervention, the documentation, and the organization of the chart were all reviewed and included in the case-by-case commentary. Sites were invited to respond with comments and questions on this process, and they in general relayed that they felt it to be a positive learning experience:

The final training and technical assistance meeting was held on April 27-28, 1992 in Cincinnati, Ohio. This meeting included case managers from both Model A and B sites. Topics covered during this training included methods to keep people with dementia out of institutions, maximizing appropriate use of demonstration services, the appropriate use of support groups, and issues surrounding the demonstration wind-down and the integration of treatment group clients back into the normal community service system.

Other training and technical assistance activities have included the following:

- All calls verifying the status of clients who are possibly receiving case management from another source were completed by the training and technical assistance coordinator. At the beginning of this process, criteria (outlined above) were established for what constituted a roughly equivalent form of case management to that provided by the demonstration. These criteria were then used to assign cases to "rollover" or "non-rollover categories."

- The development of appropriate criteria for the use of liquid nutritional supplements with Alzheimer's clients. Two types of indicators (medical and environmental) were developed to assist in identifying a situation where the use of a liquid diet might be considered to be an appropriate intervention for a person with dementia. These criteria were then adopted for use across all sites.

- Pretesting of the intake and 6-month follow-up instruments for length and ease of administration and understanding of questions was completed by IHA staff prior to the introduction of these instruments into the field.

- Finally, during the demonstration implementation phase, sites called in on an as-need basis on the average of about once a week (across all sites) for information/consultation or simply discussion on a variety of topics related to their day-to-day work in the field. Often they wished to discuss or have clarified matters pertaining to expectations of the demonstration or HCFA policies as they related to the demonstration. Among issues discussed have been whether or not people with Multiple Sclerosis are appropriate for the demonstration, redefinitions of rollovers for certain cases, and determining responsibility for transporting clients when they enter or leave a health facility.

On occasion case managers have needed advice on how to deal with a difficult situation, such as how to talk to a physician when the case manager is certain that alternate types of medication are needed (solution: have the consulting physician for the demonstration site talk with the M. D. directly), or how to handle a sticky situation where a caregiver thought she had fallen in love with her case manager (assign a new case manager of the same gender as the caregiver).

Often, case management staff simply wish for assistance with a particularly difficult case. Some of the more interesting consultations have involved:

- The caregiver who simply left her husband who had Alzheimer's disease on the front porch of the demonstration project office, phoned her case manager to tell him the client was there, and checked herself into the hospital where her physician said she was not to be disturbed.
- The client who, although going to an Alzheimer's day care center, kept loaded guns in the house and for years physically abused his wife. This was a situation which had continued for some time in spite of regular visits from a VA psychiatrist who apparently had not seen fit to either remedy or report the situation until our case manager became involved.
- The case where, when the case manager went out to do the assessment, she realized the "caregiver" was more severely psychiatrically impaired than the client and had to make arrangements to institutionalize the caregiver before the client's needs could be addressed.
- The case where two older sisters who are in their nineties are caregivers for their youngest sister who is totally bedridden and unable to recognize her surroundings. The two older sisters have learned to provide almost a skilled level of nursing care around the clock for their youngest sister and plan to continue to do so until she dies.

As is probably to be expected in this type of demonstration, the site staff have uncovered many heart rending and poignant situations where caregivers and their care receivers are making heroic efforts to survive in the community against overwhelming odds. The efforts of the case managers to assist caregivers in these situations are often extremely creative and above and beyond the call of duty. They have become experts at drawing on both informal and formal resources in order to support caregivers in these efforts. The case managers have informed us that the skills and abilities they have learned in order to do this have been acquired as a result of their work in the demonstration. If nothing else, the demonstration has helped them understand that it is possible to make the process of caring for someone with Alzheimer's disease a less stressful and more manageable experience for caregivers and patients alike.

Chapter Six

DESCRIPTION OF THE DEMONSTRATION SITES

The congressional mandate for the demonstration specifies that the evaluator provide a description of the demonstration sites and the project's implementation process. Sites visits were conducted at each of the eight sites during the months of June and July 1990. This time frame was selected so the sites would have enough time to "iron out the wrinkles" associated with the beginning of a major demonstration project but early enough so that implementation issues could be adequately documented.

A mixed methodology was employed combining a semi-structured questionnaire and the use of probing questions during the site visit discussions. The questionnaire was mailed to site directors prior to the site visit so staff would have an opportunity to prepare responses to the questions. The questionnaire contained questions regarding: 1) the history and sponsorship of the demonstration; 2) the interorganizational structure of community agencies leading the local demonstration implementation effort; 3) the local service environment of the demonstration site; 4) client outreach and enrollment activities; 5) case management services; and 6) demonstration service utilization patterns. Questionnaires were developed for project directors, Alzheimer's Association representatives, service providers, local long-term care system experts, case managers/case aides, case management supervisors, host agency directors, and outreach-intake workers.

Additional data used for the site descriptions were derived from information reported on a monthly basis by each site through monthly site reports. These reports provided site-specific information on: 1) tracking of client applications; 2) tracking of active clients; 3) tracking of case management activity; and 4) accomplishments or difficulties encountered during the month.
The descriptions generated from these data are reported below by type of model (i.e., Model A [1:100 case manager-to-client ratio and a low expenditure service cap] and Model B [1:30 case manager-to-client ratio and a high expenditure service cap] sites) and by site.

At the end of the chapter a brief summary of key program characteristics for each site is presented by model to facilitate cross-site comparisons. Model A sites are summarized in Figure 6-1, and Model B sites are summarized in Figure 6-2.

MODEL A SITES

URBANA, ILLINOIS - CARLE CLINIC ASSOCIATION

History and Sponsorship

The Medicare Alzheimer's Disease Demonstration in Illinois is sponsored by the Carle Clinic of Urbana-Champaign Illinois. Carle Clinic was started by two physicians in 1931 and was based on the model of the Mayo Clinic where the two doctors trained. In 1946 the organization split into two parts; one is a private, for-profit physician group corporation called the Carle Clinic Association. The other is a non-profit holding company called the Carle Foundation. The Carle Clinic Association is one of the largest private physician group practices in the country with a budget of over $120 million annually. The Carle Foundation owns and operates the 283-bed Carle Foundation Hospital, the second largest outpatient facility in Illinois with over 200 physicians practicing in 38 medical and surgical specialties and subspecialties. The hospital serves as the area's Level I trauma center and serves nearly 2,000 patients daily.

Carle Clinic Association and the Carle Foundation (either together or singularly) own and operate a full range of vertically integrated health care services which include a home health agency, a chain of retail pharmacies, durable medical equipment companies, a skilled nursing facility with two distinct Alzheimer's units, and a retirement housing development. The units form the core components of Carle's regional referral center in Urbana, Illinois.

With Champaign-Urbana as the referral center and major hub for in-patient and specialized care, the Carle system provides primary care through a network of branch clinics in five major service hubs: Champaign, Danville, Bloomington-Normal, Charleston-Mattoon, Mahomet, Monticello, Rantoul and Tuscola. Each branch clinic, staffed by Carle physicians, uses the local community services and networks with local providers to create smaller "hubs" of service that serve areas of an approximately 30 mile radius to that location. Carle expects to add two new service hubs in the future in Decatur, Illinois and Terre Haute, Indiana.

The Carle Clinic Association also has established the Carle Care HMO in 1980 to meet the growing demands for cost effective prepaid health insurance. This HMO offers group and individual coverage to nearly 100,000 members. In 1985, the Clinic and the Medical Group Management Association established a case management demonstration program for high-risk patients in the Champaign area. It was funded by the W.K. Kellogg Foundation. This program formed the basis for the proposal written by Carle Clinic in response to Medicare's request for proposal for the Medicare Alzheimer's Disease Demonstration.

The Carle Clinic and Carle Foundation were interested in expanding their programs to the growing elderly population in East-Central Illinois and felt they could build on their experience with the Kellogg case management program to provide the coordination and services needed by the Alzheimer's population. Support for the project was sought and obtained from the East-Central Illinois Area Agency on Aging, the University of Illinois-Champaign- Urbana, and the other major medical provider in the Bloomington-Normal area, Bromen Healthcare.

Intraorganizational Structure

At the beginning of the demonstration, management staff included a project director (100 percent FTE), a project manager (100 percent FTE), financial coordinator (80 percent FTE), located in the Champaign central office. Each of the four service areas have a case manager (50 percent FTE), education and training staff person (50 percent FTE), and a secretary/case assistant (100 percent FTE). Three intake workers (50 percent FTE each) are responsible for the outreach and intake duties at all five locations.

In July of 1990 enrollment projections were increased from 400 to 600 clients and the catchment area was expanded from 16 to 19 counties. Additional case manager (50 percent FTE), education and training (50 percent FTE) and secretary/case assistant (100 percent FTE staff) positions were added. A center in Peoria was established. In February of 1991 case management supervisor (100 percent FTE) and case assistant supervisor (50 percent FTE) positions were filled. Shortly thereafter, intake positions were reduced from 150 percent FTE to 140 percent FTE. The financial coordinator position was reduced to 50 percent and a 50 percent clerical support position was added. In May of 1991, enrollment projections were increased again to 800 clients, and the catchment area expanded to include 20 counties. Thus, as the enrollment increased, the Illinois catchment area was expanded, two new program centers were established, and staffing increased. In summary, the caseload build-up phase was a period of considerable change for the Illinois site.

The Illinois Medicare Alzheimer's Disease Demonstration operates fairly independently of the Carle Clinic, including having separate administrative offices from the medical center as well as site locations not affiliated with the Carle organization clinic sites. However, the larger organization provides a great deal of administrative and fiscal support to the program. In addition, the program has an advisory board made up of Carle Clinic physicians and chaired by the Carle Clinic Chief Executive Officer. The Project Director reports directly to the advisory board regarding program operations. In addition, for day-to-day management issues, the Project Director reports to the Associate Administrator for Group Practice Operations of the Carle Clinic on clinical issues and to the Vice President of Operations for administrative issues. This administrative structure has allowed the MAP program staff a good deal of control, independence, and flexibility in structuring and running the program. It also provides access for the program to the store of organizational resources contained within the Carle Clinic organization (e.g., fiscal support, marketing, and management information systems). For example, although a separate system of billing and accounting was established for the MAP program, the Carle Clinic accounting department is responsible for the cost accounting and fiscal reporting responsibilities of the project. Similarly, legal issues regarding the MAP program are handled by Carle Clinic's legal staff. The idea behind the intraorganizational structure was to develop a program that would be responsive to Medicare billing systems and would fit into the larger Carle organization, yet be able to stand alone (i.e., operate independently) if the program were successful and carried on by Carle Clinic after the demonstration was completed.

The project manager reports directly to the project director. The case management supervisor reports to the project manager. The financial coordinator, case managers, education and training staff, secretary/case assistants, and intake workers report to the case management supervisor. All demonstration staff meet monthly to discuss/plan demonstration organizational issues. Each location center staff meets weekly to go over center planning and organizational issues. Case managers meet bi-monthly at the Champaign central office to cover case review with the project director and geriatrician. The case managers also meet on alternate weeks with the project manager to discuss development and training issues. Case assistants meet weekly with the project director and project manager to cover demonstration planning and training. Finally, the intake workers meet with the project director and project manager monthly to discuss outreach and intake issues.

Figure II-1 presents a chart identifying overall responsibility for performance of key project functions for the Medicare Alzheimer's Disease Demonstration, including program administration, financial management, intake, and case management activities. Most staff were hired for the demonstration except for the project director and project manager. Direct services to clients are provided under contract by the host agency or by other service provider agencies in the demonstration's catchment area.

Program Staffing

Table II-1 shows the demonstration program's staffing pattern when the program neared its expanded enrollment goal of 600 active treatment clients in April 1991. The total number of demonstration full and part-time staff members was 19 for a total of 15.3 FTE staffing positions. There were 3.65 FTE administrative staff including the project director, project manager, case management supervisor and case managers at the five sites doing some administrative functions. There were 1.9 FTE outreach and intake staff for all sites, 2.5 FTE case management staff for all sites, 1.5 FTE education and training staff at all sites, 1.65 FTE research assistant/case aide staff for all sites, 3.85 FTE support staff at all sites, and .25 FTE other staff doing case assistant supervision at the Champaign-Urbana site.

Figure IL-1

Medicare Alzheimer's Project: Illinois
Responsibilities for Primary Project Functions

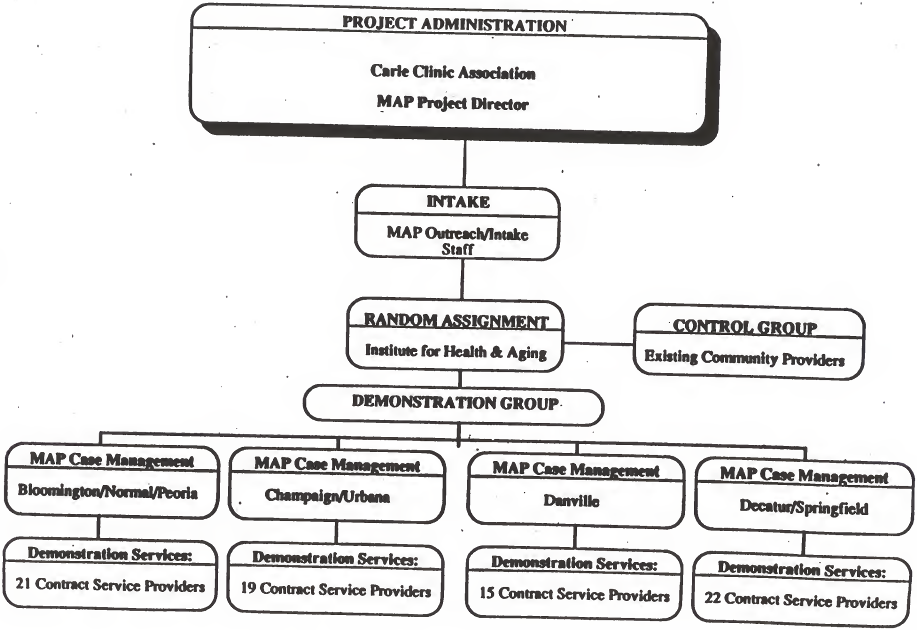

PROJECT ADMINISTRATION
Carle Clinic Association
MAP Project Director
INTAKE
MAP Outreach/Intake Staff
RANDOM ASSIGNMENT
Institute for Health & Aging
CONTROL GROUP
Existing Community Providers
DEMONSTRATION GROUP
MAP Case Management
Bloomington/Normal/Peoria
MAP Case Management
Champaign/Urbana
MAP Case Management
Danville
MAP Case Management
Decatur/Springfield
Demonstration Services:
21 Contract Service Providers
Demonstration Services:
19 Contract Service Providers
Demonstration Services:
15 Contract Service Providers
Demonstration Services:
22 Contract Service Providers

Table IL-1

Medicare Alzheimer's Project: Illinois
Demonstration Staffing Patterns

Functional Activities	(Full-Time Equivalent Staff) (April 1991)
Site 1: Champaign	
Administrative/Finance	3.25
Outreach/Intake	1.50
Case Management	.50
Education/Training	.30
Research Assistant/Case Aide	.33
Support Staff	1.17
Other	.25
Total	**7.30**
Site 2: Bloomington	
Administrative/Finance	.10
Outreach/Intake	.10
Case Management	.50
Education/Training	.30
Research Assistant/Case Aide	.33
Support Staff	.67
Other	0
Total	**2.00**
Site 3: Decatur	
Administrative/Finance	.10
Outreach/Intake	.10
Case Management	.50
Education/Training	.30
Research Assistant/Case Aide	.33
Support Staff	.67
Other	0
Total	**2.00**
Site 4: Danville	
Administrative/Finance	.10
Outreach/Intake	.10
Case Management	.50
Education/Training	.30
Research Assistant/Case Aide	.33
Support Staff	.67
Other	0
Total	**2.00**
Site 5: Peoria	
Administrative/Finance	.10
Outreach/Intake	.10
Case Management	.50
Education/Training	.30
Research Assistant/Case Aide	.33
Support Staff	.67
Other	0
Total	**2.00**
TOTAL STAFF	**15.30**

Staff Experience

While there was some difficulty in finding staff with extensive Alzheimer's or dementia experience, the demonstration had no difficulty in finding competent and experienced staff to conduct the project. The project director was interested in finding staff with nursing experience, aging experience, and, then if possible, Alzheimer's experience. The project director, a Ph.D. and RN, had been working in the Clinical Studies department of Carle Clinic and had been supervising the Kellogg case management program. She transferred over to run the Illinois Medicare Alzheimer's Disease Demonstration. The case management staff were hired from outside the Carle organization. All were nurses (RNs and an LPN with a masters degree) and have worked in gerontology and/or community-based long term care for many years. The project manager, hired from outside Carle Clinic, has a master's in Psychology and worked with dementia patients in community health. The support staff have various degrees in business or office support experience. All the intake workers have bachelors degrees and have worked in social services with the elderly for many years.

Special training and education sessions regarding Alzheimer's disease and related disorders, and in working with dementia patients and their caregivers, were provided by Carle Clinic consultants (e.g., the staff geriatrician and neurologist) and VA hospital staff. Informational materials were also obtained from the National Alzheimer's Association in Chicago. Initial training and ongoing inservice support encompassed the etiology of the disease, dealing with difficult behaviors, caregiving, and legal issues.

SERVICE ENVIRONMENT

The Community Long Term Care Service System

The Medicare Alzheimer's Disease Demonstration operates out of six service centers out of four locations in East-Central Illinois, including the administrative central office in Champaign, Illinois and site locations in Danville, Decatur, and Peoria. The demonstration covers the following 20 counties in Central Illinois: Champaign, Christian, Coles, Dewitt, Douglas, Edgar, Ford, Iroquois, Livingston, Logan, Macon, McLean, Moultrie, Peoria, Platt, Sangamon, Shelby, Tazewell, Vermillion, and Woodford.

Illinois has a population of 1.9 million persons 60 years of age and older. By the year 2000, there will be 2 million elderly, or 17 percent of the state's population. Illinois ranks sixth in the nation for percentage of population 55 or older. About one in every five persons in Illinois is 55 or older. Currently, those 85 or older make up 9 percent of the 65 and older population but by 2040, those 85 or older will grow to 19 percent of Illinois population. Roughly 25 percent of the 55 or older population live in the Chicago area while another 20 percent reside in suburban Cook County. In 1980, approximately 90 percent of those 60 or older in Illinois were White, 8.4 percent were Black, 1.3 percent were of Hispanic origin, and .6 percent were of other races. Thus, minorities comprise approximately 10 percent of the over-60 population in Illinois.

These 20 counties are predominately rural with four major urban centers, Bloomington-Normal, Decatur, Peoria and Urbana-Champaign. Rural communities are facing serious challenges in serving the elderly with a growing need for health, long-term community care, and transportation services. Specifically, rural areas are said to need respite care for families providing constant care for older persons. There is also a shortage of qualified home care workers due to low job prestige and inadequate wages, benefits, and travel allowances. Transportation is a major concern for most older people and the East-Central part of Illinois is said to be in need of more funds and vehicles to provide door-to-door, demand-response services to link seniors in rural areas to health care, social services, senior dining programs, and senior centers.

East-Central Illinois is served primarily by the East-Central Illinois Area Agency on Aging, Inc. which plans, coordinates, and advocates for the development of a full range of services to promote the health, independence, and dignity of older persons and helps families carry out their roles as caregivers in East-Central Illinois. These services include access services such as case management, information and referral, outreach, transportation and escort services; community-based long-term care services such as home delivered meals, home health, homemaker, chore/housekeeping, home repair, in-home respite care, and adult day care; community-based services such as congregate meals, legal assistance, counseling, and multi-purpose senior centers; and services to seniors in long-term care facilities such as a sub-state Ombudsman program and coordination with other community-based services for seniors.

Services are somewhat limited and accessibility uneven in the Illinois Medicare Alzheimer's Disease Demonstration catchment area. The only case management program available in the East-Central Illinois catchment area is through the Illinois Department of Aging Case Coordination Units (CCU). This program provides an initial evaluation visit to the family that is available to everyone. In order to receive funded services and ongoing case management, individuals must meet asset guidelines, as well as functional assessment standards. There are a limited number of case managers and some serve more than one county. There is one geriatric assessment clinic and one Memory Disorder Clinic in the catchment area. There is one designated information and referral agency in each of the 20 counties. Hospitals, mental health centers, and social service agencies throughout the region also provide information and referrals. There is at least one Medicare certified home care agency in each of the 20 counties. There are a very limited number of occupational therapists, physical therapists, and speech therapists available.

Homemaker/personal care services are available throughout the 20-county area but there is a consistently low number of workers attracted to this work. Part of this staffing retention problem stems from poor wages. There are meal programs available throughout much of the area, but there is a problem with delivery in the rural areas and very limited ability to provide special meals. Adult Protective Services and mental health counseling for the elderly population are limited. Transportation is available in most larger communities but availability in the rural areas is minimal and not able to adapt to individual schedules.

Hospice and adult day care services are limited. There are ten half-day adult day care programs that serve portions of ten of the twenty counties. This leaves ten counties without adult day care services. Respite care, training for informal caregivers, and support services for informal caregivers are minimally available. Finally, there is an inadequate number of senior citizens housing facilities. At this point, there is no congregate or foster care housing, only a few board and care homes, and a few continuing care retirement communities. The latter serve those with higher incomes. ICFs are available, but in many areas these function with a waiting list. Both ICFs and SNFs have staff retention problems apparently due to low wages.

Consistent with the lack of services within the Illinois Medicare Alzheimer's Disease Demonstration catchment area, there are access problems for dementia patients. The usual entry points for dementia patients to the community-based care system include physicians, hospital discharge planners/social service staff, and CCUs. Among the reported barriers to services for dementia patients are service providers' reluctance to serve combative or aggressive patients, the inability of home care workers to cope with dementia patients (e.g., they have no special training in dementia), the high cost of private duty respite care, and denial of the disease by dementia patients and their caregivers.

There is a need for more nursing homes which specialize in the care of dementia patients since many facilities in East-Central Illinois are not equipped to provide 24 hour monitoring of dementia patients who wander. Due to concerns about liability, some nursing homes have attempted to discharge dementia patients alleging that they are a "harm to themselves and others." It is the opinion of some long term care experts in the East-Central Illinois catchment area that the current practice of "mixing" dementia patients with other residents in nursing homes creates a disruptive atmosphere, denies the dementia patients proper care and treatment, and robs the other residents of their privacy. Furthermore, some dementia patients do not need intermediate or skilled nursing home care but are placed in nursing homes because the family refuses or is unable to provide care at home. The unnecessary placement of dementia patients in ICF and SNF facilities reduces the availability of nursing home care to other patients. Finally, more specialized housing and treatment facilities are said to be needed for dementia patients.

Alzheimer's patients have access to some specialized services within the Carle Clinic organization. The medical practice has a geriatrician and a neurologist on staff to provide consultations, and the Carle nursing home has two dementia units as well as the adult day care center. There are also a few drug studies going on in the Champaign-Urbana site which focus on Alzheimer's patients.

The Community Care program (Medicaid waiver program) competes with the Alzheimer's demonstration for clientele. The Community Care program requires an income of under $10,000, and has other asset limitations. There are annual income and functional status re-evaluations. The Community Care program benefits include day care, homemaker/chore, and case management. There is no waiting list of services once eligible. The program is offered in all of the demonstration locations. The strength of the program varies depending on the local implementation contracts. A limited number of persons in the Community Care program were accepted into the demonstration treatment or control groups according to the randomization protocol.

Table IL-2 summarizes the demonstration catchment area by scoring community-based services according to their availability, accessibility, and quality of care. The scores were obtained from knowledgeable spokespersons in the service area. The scores for each of the service types reflect the above discussion regarding the limited access to services for many elderly in the 20 county area. With a total score of 87 points out of a possible 225, the Illinois Medicare Alzheimer's Disease Demonstration catchment area is characterized as a "fair" long term care system.

Table II-2

Medicare Alzheimer's Project: Illinois
Community Spokesperson's Ratings on the Availability, Accessibility, and Quality of the Long Term Care Service System

Service Type	Maximum Points[a]	Catchment Area Score[b]
Integrative Services		
Case Management		4.5
Geriatric Assessment		2.0
Information and Referral		7.0
Subtotal Points	27	13.5
Home Health Care		
Skilled Nursing		5.0
Therapies		4.0
Social Services		2.0
Home Health Aides		4.0
Subtotal Points	36	15
Home Support Services		
Homemaker/Chore Services		5.0
Personal Care Services		5.0
Meals (home & community)		3.0
Adult Protective Services		3.0
Mental Health Counseling		3.0
Transportation		4.5
Subtotal Points	54	23.5
Special Purpose Services		
Hospice Care		3.0
Day Health Care		4.0
Social Day Care		3.0
Respite Care		4.0
Training for Informal Caregivers		2.5
Support Services for Informal Caregivers		2.5
Subtotal Points	54	19
Living Arrangements		
Senior Citizens Housing		5.0
Congregate Housing		1.0
Board and Care/Residential Care		1.5
Foster Care		1.0
Intermediate Care Facility		4.5
Skilled Nursing Facility		3.0
Subtotal Points	54	16
TOTAL POINTS[c]	225	87

[a] Each service type was ranked on a scale of 0 to 3 on the dimensions of availability (0=None, 1=Low, 2=Medium, 3=High), accessibility (0=None, 1=Low, 2=Medium, 3=High) and quality (0=None, 1=Low, 2=Medium, 3=High). The service score for each service type could range from 0 to 9. The maximum service points within service subgroups and the total possible points across all long-term care services within a catchment area are shown in column 2.

[b] In catchment areas serving more than one county, the ratings for each county were totaled and then an average score was calculated.

[c] Score range = 0 to 255; 0-75 = Poor Long Term Care Service System; 76-150 - Fair Long Term Care System; 151-255 - Well Developed Long Term Care System.

Demonstration Service Providers

The host agency in the Illinois Medicare Alzheimer's Disease Demonstration is the sole provider of demonstration case management services. Originally, as the program attempted to establish service contracts with outside community-based service providers, they found that many of the providers were wary of the "Carle Organization" coming into their counties. This was seen as an attempt to "take over their territory." Accordingly, several providers were reluctant to enter into contracts with the program or to refer potential clients. This was especially true when developing referral contacts with non-clinic physicians. In time, the MAP staff were able to develop good networking and working relationships with most providers in its catchment areas. In the end, the program has developed a number of provider contracts in each of its six service areas.

The primary reasons for subcontracting are: the host agency does not offer the service; the client already has an ongoing relationship with another provider; and/or the client lives in an area where the service is geographically more accessible through another provider. Case managers are given a great deal of freedom in determining the appropriate service provider for each client. The project director and project manager are responsible for negotiating the contracts needed within the catchment area. Generally, the demonstration project is matching each service provider's prevailing rate.

Carle Clinic provides Medicare certified home care services for the Danville and Champaign sites while Carle Medical Supplies provides medical supplies and equipment from its Champaign location to all five MAP locations (Champaign, Bloomington, Danville, Decatur, and Peoria). The Peoria site contracts with the same service providers as the Bloomington/Normal site. Carle Foundation provides adult day care for the Champaign-Urbana center. The remainder of the services are subcontracted. The Illinois Medicare Alzheimer's Disease Demonstration subcontracts with a total of 77 service providers, some serving clients in more than one county, in the 20-county catchment area. Subcontracted services include:

- Bloomington/Normal/Peoria catchment area: 21 service providers
- Medicare certified home health care
- home delivered meals
- adult day care
- homemaker/housekeeper/chore services
- medical supplies, adaptive & assistive equipment
- durable medical equipment, consumable care goods
- companion services
- counseling
- transportation
- outreach

- Danville catchment area: 15 service providers
- medical supplies, adaptive/assistive equipment, durable medical equipment, consumable care goods
- transportation
- homemaker/housekeeper
- home delivered meals
- chore services
- adult day care
- certified home care services
- family counseling, mental health services

- Decatur catchment area: 22 service providers
- medical supplies, adaptive/assistive equipment, durable medical equipment, consumable care goods
- transportation, outreach
- homemaker/housekeeper/chore services
- companion services
- home delivered meals
- Medicare certified home care
- adult day care

- Champaign-Urbana catchment area: 19 service providers
- adult day care
- Medicare certified home care
- medical supplies, adaptive/assistive equipment, durable medical equipment
- family counseling, mental health services
- homemaker/housekeeper/chore services
- transportation services

Outreach and Enrollment

Program Census

The 20 counties served by the Illinois Medicare Alzheimer's Disease Demonstration program cover an area of 13,364 square miles and accounts for over 237,880 persons 60 or older. The largest elderly concentrations in the 20 county area include Sangamon and Peoria counties, each accounting for 14 percent of the area's total population 60 or older; Macon county with 10 percent of the area's total population 60 or older; Champaign and Tazewell counties each accounting for 9 percent of the area's total population 60 and older; McLean and Vermilion counties each accounting for 8 percent of the area's total population 60 or older; and Coles County with 7 percent of the total population 60 or older. The rest of the counties' over-60 populations ranged from a high of 6 percent to a low of 1 percent. Over 10 percent of the area's total over-60 population live in poverty while 28 percent are living alone. Thirty-five percent of the 20-county area's population are 75 or older. Fifty-six percent of the residents of the original 16 counties lived in rural areas. Due to the designation of county wide Standard Metropolitan Service Areas in the 1990 census for those counties with metropolitan centers, current rural residency figures are not available.

Almost 4 percent of the area's total population are minorities including 3.2 percent Black, .09 percent American Indian, .23 percent Asian, .9 percent Hispanic, and .01 percent Other minority. Sixty-six percent of the total minority population in the original 16 counties live in poverty. Over 5 percent of the area's total over-60 population reside in nursing homes and there are almost 10,000 licensed nursing home beds within the original catchment 16 county area.

Demonstration service centers are located in Champaign-Urbana and serve Champaign, Coles, Douglas, and Ford counties; in Bloomington and serve Livingston, McLean, Peoria, Tazewell and Woodford counties; in Danville and serve Edgar and Vermilion counties; and in Decatur and serve Christian, DeWitt, Macon, Piatt, Sangamon, Shelby, and Moultrie counties.

Under the assumption that 4 percent of the elderly would be cognitively impaired as a result of Alzheimer's or related dementias, it was estimated that approximately 5,352 elderly would be eligible for the demonstration. The Illinois demonstration's initial project census was 400 (200 treatment clients and 200 control clients). Each location matched the treatment client census with an equal number of control group clients. The treatment/control group issues are discussed in the research design section of this report.

In July 1990, the original census goals were raised by 200 cases (100 treatment and 100 control) to a total of 600 active treatment and control clients. In May 1991, enrollment projections were increased again, from 600 to 800 active clients. By April 30, 1991, the Illinois site had enrolled a total of 728 clients, of which 22 percent (or 163 clients) attrited from the sample due to death, institutionalization, or moved out of catchment area. Thus, the final sample census was 565 clients (284 treatment and 281 control) as of April 30, 1991. Overall, the Illinois site has been successful in reaching its enrollment goals, averaging 53 applications per month during the 17-month enrollment period of the demonstration.

Difficulties Encountered Reaching Enrollment Goals

For the most part, the Illinois demonstration was able to meet its projected client census goals throughout the caseload build-up phase. However, there were some periods during caseload buildup when they were behind in their projected census. In addition, unanticipated difficulties in locating and recruiting eligible clients arose, which required changes in some outreach procedures.

Outreach efforts included advertising, radio spots, presentations to provider groups, networking, feature stories in local newspapers, as well as extending the service delivery catchment area to Peoria county early in the demonstration, which had not been a site location in the original grant. However, referrals were somewhat slow in the beginning but, as the program became known, referrals and enrollment increased. The major reason for slow referrals had to with the intense competition between healthcare providers in the catchment area. Carle Clinic and Bromen Healthcare are the two major providers and there was reluctance on the part of many of the non-Carle providers to refer patients to the Medicare Alzheimer's Disease Demonstration. Special networking efforts by the Medicare Alzheimer's Disease Demonstration staff overcame many of the "perception" problems that led to low referrals by non-clinic providers (e.g., fears that clients referred to the Medicare Alzheimer's Disease Demonstration program would become "Carle Clinic" clients, turf concerns).

Surprisingly, one of the more resistant groups to refer clients turned out to be Carle Clinic physicians themselves. While a great deal of work had been done by outreach and administrative staff to introduce the Medicare Alzheimer's Disease Demonstration program to providers outside the Carle Clinic organization; traditional efforts to get the program known within the organization did not work very well. Thus, not as many Carle Clinic patients were being referred to the program as expected. It was discovered that physicians, no matter where they practiced, just did not take into account the social service needs of their dementia patients. Most were primarily concerned with the medical aspects of the disease and, though they might have heard about the MAP program, did not think of it when seeing patients who might qualify for the program.

Halfway through the caseload build-up phase, the MAP staff decided to review all patient files by diagnosis in a number of medical specialties to which dementia patients would be treated within the clinic to identify potential program candidates. The patient's physician was then contacted to reintroduce them to the program and to see if they objected to the MAP program contacting the client to see if they would be interested in the program. This identification system, along with more stringent efforts at getting word out about the MAP program to the physicians, increased the number of in-house referrals made to the program.

When the project initially began enrolling clients in December of 1989, it was a full 13 months after the first local announcement that Carle Clinic had been awarded the demonstration grant. By December, the project had a "waiting list" of applicants to be enrolled. However, a good proportion of applicants on the waiting list were no longer eligible because they had been permanently institutionalized, were deceased, or were found to have an ineligible diagnosis based on the physician referral form.

Table II-3 shows the number and proportion of cases who terminated during the application process and the reasons for termination by quarter through June 1991. As can be seen in Table II-3, a total of 331 applications were terminated prior to the

Table II.-3

Medicare Alzheimer's Project: Illinois
Reason for Termination During the Application Process by Quarter
(January 1990 through June 1991)

REASON	1990								1991				TOTAL	
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Outside of Catchment Area			49	56	2	4	3	3	8	20	1	2	63	19
Ineligible Diagnosis	6	32	5	6	5	11	28	30	11	27	10	22	65	20
Did Not Have Medicare Part A and Part B	2	11	1	1	4	8	12	13	1	3	10	22	30	9
Unwilling to Consider Co-Payment	1	5											1	-1
Refused to Sign Consent Form			1	1									1	-1
Refused to Accept Possibility of Control Group Assignment														
Found to be in Case Managed/ Duplicate Provider System														
Refused to Comply with Demonstration Requirements[a]	1	5	10	11	16	34	6	7	3	7	1	2	37	11
Institutionalized	6	32	8	9	9	19	17	19	14	34	12	27	66	20
Died	2	11	1	1	6	13	7	8	1	3	1	2	18	5
Physician Failed to Return Physician Form	1	5	1	1	2	4	1	1					5	2
Could Not Locate for Intake Interview			5	6	3	6	2	2	1	3	2	4	13	4
Duplicate Applicant							2	2					2	1
Not Interested[b]			7	8			14	15	1	3	8	18	30	9
TOTAL[c]	19	101	88	100	47	99	92	100	40	100	45	99	331	100

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] e.g., intake interview, follow-up interviews, case management.

[b] The two primary reasons reported under the "not interested" category were the client's family members could not all agree about participation or the potential client did not want to be in the project.

[c] Percentages greater than or less than 100 due to rounding.

randomization of the client. The most frequent reasons for terminating an application were: the client had an ineligible diagnosis (20 percent) or the client had been institutionalized (20 percent); the applicant lived outside of the program's catchment area (19 percent); the client or their caregiver refused to comply with the demonstration requirements (11 percent); the client did not have Medicare A and B (9 percent) or was "not interested" (9 percent); the client died (5 percent); the client/caregiver could not be located for an intake interview (4 percent), or the physician failed to return the physician referral form (2 percent).

CASE MANAGEMENT SERVICES

Compliance with the Case Management Model

The Case Management Model is one of the primary interventions being tested under the demonstration. To help ensure that each site maintained the appropriate case manager-to-client ratio during the caseload build-up phase of the demonstration, the sites were required to provide monthly reports on the amount of time each case manager was spending on case management related activities and the number of active cases for each case manager. With this information, it was possible to monitor the case manager-to-client ratio to determine if the project was complying with the Model A criteria of one case manager per 100 clients. The sites were allowed a 5 percent variance above or below the client-to-case manger ratio during the caseload build-up phase due to addition of clients, transitions in cases, addition of staff, etc. For the Model A sites, this variance could range from 95 and 105 active cases per case manager and not be out of compliance with the Model A criteria (e.g., new cases coming on; clients terminated due to death or institutionalization).

To be in compliance with the 1:100 case management model in the Model A sites, the case managers should be spending, on average between 1 and 1 1/2 hours per month per active client. Table II-4 shows the case manager-to-client ratio over the case load buildup phase, February 1990 to June 1991/April 1991. The data in Table II-4 show that the Illinois sites' case manager-to-client ratios ranged from a low of 1 case manager to 34 clients in February 1990 to highs of 1 case manger to 106 clients in December 1990 and May 1991 and one case manager to 111 clients in June 1991. The site was not truly in compliance with the case manager-to-client model until December 1990 and even then, the ratios fluctuated above as well as below the 1 to 100 model into April/June of 1991. Based on the data in Table II-4, the case managers in the Illinois sites were spending more than the 1 to 1 1/2 hours per client as required in the Model A ratio.

Case Management Activities

Table II-5 shows a distribution of case management time among a variety of activities. The Illinois site was unique in that each case manager was filling two part-time positions; one as case manager and a second as caregiver educator. This was essential to the decentralized model required by the large, rural setting that

Table II-4

Medicare Alzheimer's Project: Illinois
Compliance with the Model A Case Manager-to-Client Ratio of 1:100[*]

Month	Case Manager-to-Client Ratio[a]
February 1990	1:34
March 1990	1:35
April 1990	1:71
May 1990	1:79
June 1990	1:95
July 1990	1:88
August 1990	1:90
September 1990	1:83
October 1990	1:86
November 1990	1:81
December 1990	1:106
January 1991	1:94
February 1991	1:86
March 1991	1:88
April 1991	1:102
May 1991	1:106
June 1991	1:111

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] The average case manager-to-client ratio was derived by dividing the total hours each case manager spends on case management activities each month by the number of clients assigned to the case managers that month. The average hours spent per case-managed client were then converted to a ratio by dividing the number of hours per client by the total hours worked in an average month (i.e. 168 hours). In the Model B projects, with a 1:100 case manager to client ratio, each client should receive approximately 1.5 hours of case management per month.

[*] The sites were allowed a 5% variance above or below the case manager-to-client ratio during the caseload build-up phase due to additions of clients, transitions of cases, additions of staff, etc. For the Model A sites, this variance could range from 95 to 105 clients per case manager and not be out of compliance with the Model A criteria.

Table IL-5

Medicare Alzheimer's Project: Illinois (All Sites)
Case Management Activities

Activity	Percent Time Spent in Each Activity[a]	
	Case Managers[b]	Case Aides[c]
Outreach and Intake	0	23
Initial Assessment	20	0
Initial Care Planning/Service Arrangement and Costing of Care Plan	24	23
Case Conferences	5	5
Service Monitoring/Follow-up	20	13
Caregiver Education and Training	0	8
Public Relations	0	0
Administrative/Supervisory Meetings, Reports	0	11
Record Keeping/Data Entry	11	11
Local Travel	20	6
Other	0	0
Total	**100**	**100**

[a] Each case manager completed a time study allocating the total number of hours he/she typically spent during a week in various activities. The time study was completed in the summer of 1990, during the case load build-up phase of the demonstration.

[b] Illinois case managers worked only 50 time as case managers. The other half of the time was spent in training and educational activities and administrative meetings.

[c] Case managers were performing substantial case manager support activities.

constituted the Illinois catchment area. Case assistants were performing many of the service arrangement functions that do not require the higher level skills of the case managers (i.e., calling providers to make specific service arrangements as authorized by the case manager and confirming service times with the family caregivers). Most of the other demonstration sites did not use case aides in this manner.

As can be seen in Table 5, case managers were spending the most time in initial care planning/service arrangement activities (24 percent); and about equal amounts of time in initial assessments, service monitoring/follow-up activities, and in local travel (20 percent each). Eleven percent of case managers' time was spent in record keeping and data entry activities and 5 percent in case conferences.

Case aides were spending the most time in outreach and intake activities and in care planning and service arrangement activities (23 percent each), which was equal to the amount of time spent in this activity by case managers. Thirteen percent of case aides' time was being spent in service monitoring and follow-up activities, which was not much less than case managers spent in this activity. Finally, administrative meetings and record keeping took approximately 11 percent each of case aides' time and local travel about six percent. Again, this substantive use of case aides to support case manager activities was an unusual characteristic of the Illinois demonstration site.

Demonstration Service Utilization Patterns

During the caseload build-up phase of the demonstration, the number of active clients rose steadily. As shown in Table IL-6, by the second quarter of 1991, the site had 284 active clients enrolled in the program. The five locations averaged 182 active clients per month. Of particular interest is the average number of clients receiving case management-only services. While the Illinois site started relatively high in providing case management services only (37 percent in the first quarter of 1990, 24 percent in the second quarter of 1990), by the third quarter of 1990, the percentage of case managed-only clients had fallen to 17 percent and continued to drop in subsequent quarters. By the second quarter of 1991, the percentage of case management-only clients had declined to 12 percent. This trend was somewhat different at two of the other Model A Medicare Alzheimer's Disease Demonstration sites where case management-only clients were a consistently higher proportion of all active clients across all six quarters under review.

Reasons for clients to choose case management only include the fact that some clients are newly diagnosed and do not, as yet, require additional services or there may be a discrepancy between what the client/caregiver think they need and what the case manager and/or the demonstration have to offer. For example, the case manager may feel that adult day care services would be the best service (or in locations where a variety of service options may not be available, the ONLY service) for the client but the caregiver is not willing to be separated from the client (or vice

Table IL-6

Medicare Alzheimer's Project: Illinois (All Sites)
Services Use Patterns by Quarter
(March 1990 through June 1991)

Service Use	1990								1991			
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Average Number Active Treatment Clients per Month	49	100	114	100	165	100	230	100	256	100	284	100
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	17	35	74	65	123	75	178	77	211	82	239	85
Average Number Treatment Clients Receiving Case Management Only	18	37	27	24	28	17	36	16	35	14	35	12
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	14	28	13	11	14	8	16	7	10	4	10	3

versa) or the caregiver is unable to get the client to the program (or even be able to have the client ready to go when the program can provide transportation). Thus, the effort required of the caregiver to get the client "ready" for the services may outweigh the potential benefits and thus, the caregiver will decline. Finally, reluctance to accept services may be due to the "stigma" attached to Alzheimer's and thus, the caregiver may refuse other services until the situation becomes unmanageable.

ROCHESTER, NEW YORK - MONROE COUNTY LONG TERM CARE PROGRAM, INC.

History and Sponsorship

Three agencies sponsor the Medicare Alzheimer's Disease Demonstration in Rochester, New York: the Monroe County Long Term Care Program (ACCESS), the Visiting Nurse Service of Rochester (VNS), and the Monroe County Health Department (MCHD). ACCESS is the primary agency. The proposal was reviewed and supported by the ADRDA, Rochester.

ACCESS, the VNS, and MCHD have together implemented two major HCFA demonstrations of coordinated community-based care as well as a randomized case management study funded by the Robert Wood Johnson Foundation. From 1977 to 1986, Medicaid and/or Medicare waivers allowed the three organizations to provide community-based programs for long term care patients in Monroe County. The previous demonstrations/studies conducted in Monroe County included a number of patients with Alzheimer's disease and related disorders and the clients remain a significant portion of the caseloads of the three agencies today. Many of the staff who are now participating in the MAP demonstration were with ACCESS during the previous Medicare demonstrations, including the Executive Director of the ACCESS program.

The ACCESS program was established in 1975 as the community-based program designed to coordinate and develop alternatives and administer funds for long term care for the elderly and adult disabled in Monroe County, New York. Services provided since its inception include information and referral as well as case management. Over the years, ACCESS has developed a number of long term care programs, including a Medicaid Section 1115 waiver program (1977-1985), the first HCFA demonstration program to implement comprehensive assessment as part of case management for long term care patients; a Medicare Section 222 waiver demonstration program, ACCESS: Medicare (1982-1986), which financed comprehensive assessments and case management for Medicare patients at risk of institutionalization and provided 100 days of home care and 100 days of nursing home care annually; a team model of case management funded by the Robert Wood Johnson Foundation (1983-1985); and ACCESS: Select, a self-pay information and referral, assessment, and service coordination/monitoring service. ACCESS: Select is a member of Work/Family Elder Directions' nationwide network of counseling and referral agencies created to serve corporate employees and retirees and their families.

The central feature of ACCESS has been its case management program for long term care patients living at home. The average daily census of the Medicaid case load managed by ACCESS has increased from 182 in 1978 to 900 in 1989. The self pay program has served more than 700 clients and their families since 1985 while the ACCESS:Medicare program served 2,200 clients from 1982 to 1986. In the past ten years, over 2,000 individuals with Alzheimer's disease or related disorders have been case managed by ACCESS.

Since its inception, ACCESS has been working with VNS and the MCHD to improve the effectiveness of the long term care system in Monroe County, New York. Two earlier joint efforts between ACCESS, VNS, and MCHD were carried out through the ACCESS:Medicaid Section 1115 and Medicare Section 222 demonstrations. The VNS and MCHD provided the clinical case coordination and many of the direct services these clients required. The purpose of the Robert Wood Johnson Foundation case management study was to test a new approach for managing the care of seriously chronically ill elderly living in the community.

The Visiting Nurse Service of Rochester and the Monroe County Health Department Home Health Agency are certified home health agencies. Both organizations offer a wide range of home care services to the elderly, disabled, and terminally ill. The VNS of Rochester, the first home health care agency in Rochester, was founded in 1919. VNS provides the following in-home services: skilled nursing, home health aide, homemaker/personal care aide, meals/food service, durable medical equipment, and consumable care goods. Today, VNS serves an active patient caseload of approximately 1,800 people at any given time.

The Monroe County Health Department was organized in 1958. Its home health agency differs from VNS in that it has a major health promotion and disease prevention focus. It is mandated to provide maternal and child health care, immunizations, and mental health services. The MCHD home health agency provides skilled nursing at home. The MCHD home health agency currently has 140 employees and an active caseload of 1,500 patients, excluding maternal and child health clients. Both the VNS and MCHD provide services 24 hours a day, 7 days a week and have a hotline system for evenings, nights, holidays, and weekends. Each agency has a supervisor and nurses available to make visits after hours to handle patient care problems.

As a result of its history with three case management model demonstrations, ACCESS decided to apply for the Medicare Alzheimer's Disease Demonstration award. ACCESS developed the proposal, in conjunction with VNS and MCHD as subcontractors to ACCESS, with ACCESS as the lead agency in much the same way they had worked together on past demonstration projects.

Intraorganizational Structure

Demonstration Site Location

The Medicare Alzheimer's Disease Demonstration operates out of one agency in Rochester, New York and serves all of Monroe County, New York. Early in the demonstration build-up phase, the program expanded into four adjacent rural counties including Ontario, Wayne, Livingstone, and Yates counties. The ACCESS organization is responsible for all administrative, case management, outreach and intake, and fiscal activities and houses all of the program's administrative, supervisory, case management, outreach and intake, fiscal, and support personnel.

Figure NY-1 presents a chart identifying overall responsibility for performance of key project functions for the Medicare Alzheimer's demonstration. Most staff were hired by the demonstration, but the project management staff, Intake Supervisor, Case Management Supervisor, and two of the case management staff were all ACCESS employees prior to demonstration funding. Direct services are provided to clients, under contract by VNS, MCHD, or other service providers in the Monroe County area.

Program Staffing

Table NY-1 shows the demonstration program's staffing pattern when the program was to have reached its original enrollment goals of 300 active treatment clients (and 300 control clients) in April 1991. The total number of demonstration staff members was 23 full and part-time staff working for the project for a total of 22.55 FTE staffing positions. There were 3.1 FTE administrative staff including the project director (.8 FTE), the deputy director (.5 FTE), financial staff (1.0 FTE), and case management supervisor (.8 FTE). There were 12.3 FTE) outreach and intake staff including a full-time (1.0 FTE) intake supervisor, 2 full-time outreach interns, and 6 part-time nurse intake assessors. There were 2.5 FTE case management staff responsible for case management and education and training of caregivers; 1.95 FTE research assistant/case aide staff, and 2.70 FTE support staff.

Staff Experience

The demonstration had little difficulty in finding experienced staff for the demonstration. All three agencies involved in the demonstration have very experienced management staff who have had between 8 to 15 years experience in long term care service organizations. Many of the staff of the MAP project were already on staff with ACCESS prior to demonstration funding, including the Site Director, the Director of Research and Planning, the Manager of Information Services, the Case Management Supervisor, two case managers, the Intake Coordinator, and many of the support and financial staff. Nurse Assessors and public relations interns were all hired from the outside. However, few of the staff had extensive Alzheimer's specific training or experience. One case manager has a social work degree and has worked for ACCESS since 1978 while the other case manager is an RN and has worked for ACCESS since 1987. While many of the staff had worked with Alzheimer's patients and families in the course of their work at ACCESS, none had specifically focused on Alzheimer's patients per se.

Figure NY-1

Medicare Alzheimer's Project: New York
Responsibilities for Primary Project Functions

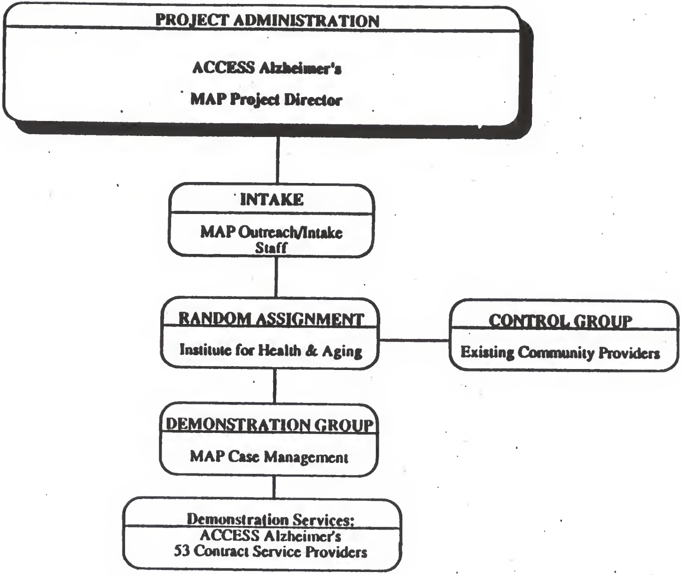

PROJECT ADMINISTRATION
ACCESS Alzheimer's
MAP Project Director
INTAKE
MAP Outreach/Intake Staff
RANDOM ASSIGNMENT
Institute for Health & Aging
CONTROL GROUP
Existing Community Providers
DEMONSTRATION GROUP
MAP Case Management
Demonstration Services:
ACCESS Alzheimer's
53 Contract Service Providers

Table NY-1

Medicare Alzheimer's Project: New York Demonstration Staffing Patterns

Functional Activities	(Full-Time Equivalent Staff) (April 1991)
Administrative/Finance	3.10
Outreach/Intake	12.30
Case Management	2.50
Education/Training	0
Research Assistant/Case Aide	1.95
Support Staff	2.70
TOTAL STAFF	22.55

The ACCESS program utilized a "brokerage" model of case management in which all direct services were subcontracted to contract agencies. However, client assessment was conducted by the ACCESS case managers. A further assessment of the client was conducted by contract agencies providing health related services, which is required by the state of New York for licensure (e.g., certified HHA agencies such as VNS or MCHD). However, these assessments tended to be more narrowly focused than the ACCESS assessments in that they concentrated on clinical needs for nursing care. The model of case management used by the ACCESS program is a brokerage model. This model is characterized by the delegation of hands-on functions such as assessment, care plan development, service delivery, and reassessment to health care providers who are not employees of the case management organization. The ACCESS case managers conduct client assessments and care planning activities, approve care plans, coordinate services, and monitor service delivery. Both the VNS and MCHD conduct clinical coordination activities, which complement the ACCESS case management activity. The community health nurses' (VNS and MCHD contract agencies) responsibilities include providing in-home nursing services and patient assessments, developing nursing care plans, coordinating cases, assessing patient response to the care plan and communicating this information to the patient's care providers, teaching patients/families, supervising home health aide and personal care aides, providing patient/family consultation regarding long and short term goals, and assisting with referral to other community resources. The case managers employed by ACCESS are generally registered nurses or social workers.

Service Environment

The Community Long Term Care Service System

The state of New York is unique in that most in-home service agencies must be licensed by the state and services in the home must be ordered by a physician. In addition, each licensed agency must conduct its own assessment on a client before providing services, even if a case manager from another agency has already conducted a client assessment. In Monroe County, the MCHD provides the physician mandated home health services along with the Department of Senior Services. All personal care, home health, and all health related services in the home, other than companion services, must be performed by specifically trained and certified personnel. This is true for all services that come under the state's licensure law. As a result, ACCESS was required by the state health department to become licensed as a home health agency when they were awarded the Medicare Alzheimer's demonstration. Services that do not come under this state licensure law include support groups, companion services, and home repair, etc. Case managers in the demonstration must have a physician sign off on their case plans. In addition, New York requires a nurse assessment prior to services being provided in the home. This is why ACCESS' contracts assessment functions with VNS and MCHD. Thus, New York is a highly regulated service delivery environment.

The long term care service delivery system within the county is characterized by a wide variety of social and health service delivery providers. Access to services by dementia patients and/or caregivers is not restricted in Monroe County. There are two dementia diagnosis clinics in the county; one, the Alzheimer's Disease and Memory Disorders Clinic, housed at Strong Memorial Hospital, which is jointly sponsored by the University of Rochester Medical Center and Strong Memorial Hospital. The other diagnostic center is the Williams Geriatric Assessment Clinic at Monroe Community Hospital.

Other Alzheimer's specific services include an Alzheimer's Disease Assistance Center, funded by the state, which provides case management and support group services and the Alzheimer's Family Outreach Center, a Monroe Community Health Department program providing fee-for-service case management, multi-disciplinary assessment, and counseling services through Monroe Community Hospital. Rochester Rehabilitation Center also provides services to dementia patients through a program called Project Reach, which assesses homebound chronically ill elderly (many of whom have dementia) and provides psychiatric home visits, care plan development, and counseling services; and the Monroe County Mental Health Department also provides services (e.g., case management) to dementia patients.

In addition, there is a 20 to 30 percent penetration by HMOs in the Rochester area (specifically, a Blue Cross-Blue Shield plan) that offers information and referral services to its members. The state of New York also has a program for dementia patients in a local nursing home with a dementia unit. There are Alzheimer's-specific respite programs and many home health aides and respite staff have had Alzheimer's specific training. Finally, there is the Wilson Special Alzheimer's Program at the Jewish Home, which is a medical and social day health program.

Other case management systems in Monroe County include four programs based on the nursing home-without-walls program. About 800 of 1,000 case managed clients from the Department of Social Services were transferred to these community-based case management programs. A total of four nursing home-without-walls programs were instituted in Monroe County. The state Medicaid program and a special New York state funded program also provide case management. The state funded program is for individuals who are above Medicaid eligibility limits but below 200 percent of the poverty level. It provides case management and home care services on a sliding fee scale.

Major access points for Alzheimer's patients to the service system come from primary care physicians, hospitals (e.g., hospital discharge planning units), home health agencies, nursing homes, and from families themselves. Barriers to access include families' and physicians' lack of knowledge of the services. A second major barrier is the cost of many of the services. Another complicating factor is the amount of time it takes to become Medicaid certified in New York. While the Medicaid program is very generous (e.g., a Medicaid certified individual can qualify for 24-hour, 7-day-a-week home care through the program), many families do not want to spend down to qualify or they have too many assets to qualify.

Table NY-2 summarizes the demonstration catchment area by scoring community-based services according to their availability, accessibility, and quality of care. The scores were obtained from knowledgeable spokespersons in the demonstration's service area. Total scores for the service types range from 0 - 255: 0 - 75 denotes a service poor long term care system; 76 - 150 denotes a medium/fair amount of services available within the service area; and a score of 151 - 255 denotes a well-developed long term care system. As can be seen in Table NY-2, the Monroe County long term care system was scored at 158.5 points, over the minimum needed to be characterized as a well-developed long term care system. Specifically, Monroe County scored 24 points (out of a total of 27) for the availability, accessibility, and quality of its integrative services (e.g., case management, geriatric assessment). Monroe County was assigned a total of 28 points (out of a possible 36) for the home health care services; a score of 34.5 (out of a possible 54) for the type of home support services available; a score of 39.5 (out of a possible 54) for special purpose services (e.g., hospice care, day care); and a score of 32.5 (out of a possible 54 points) for the living arrangements services (e.g., senior citizens housing, congregate housing).

Table NY-2

Medicare Alzheimer's Project: New York
Community Spokesperson's Ratings on the Availability, Accessibility, and Quality of the Long Term Care Service System

Service Type	Maximum Points[a]	Catchment Area Score[b]
Integrative Services		
Case Management		8.5
Geriatric Assessment		6.5
Information and Referral		9.0
Subtotal Points	27	24.0
Home Health Care		
Skilled Nursing		8.5
Therapies		4.5
Social Services		7.5
Home Health Aides		7.5
Subtotal Points	36	28.0
Home Support Services		
Homemaker/Chore Services		7.5
Personal Care Services		7.0
Meals (home & community)		9.0
Adult Protective Services		3.5
Mental Health Counseling		3.5
Transportation		4.0
Subtotal Points	54	34.5
Special Purpose Services		
Hospice Care		7.0
Day Health Care		7.5
Social Day Care		8.5
Respite Care		5.5
Training for Informal Caregivers		5.5
Support Services for Informal Caregivers		5.5
Subtotal Points	54	39.5
Living Arrangements		
Senior Citizens Housing		8.5
Congregate Housing		5.5
Board and Care/Residential Care		5.5
Foster Care		2.5
Intermediate Care Facility		5.5
Skilled Nursing Facility		5.0
Subtotal Points	54	32.5
TOTAL POINTS[c]	225	158.5

[a] Each service type was ranked on a scale of 0 to 3 on the dimensions of availability (0=None, 1=Low, 2=Medium, 3=High), accessibility (0=None, 1=Low, 2=Medium, 3=High) and quality (0=None, 1=Low, 2=Medium, 3=High). The service score for each service type could range from 0 to 9. The maximum service points within service subgroups and the total possible points across all long-term care services within a catchment area are shown in column 2.

[b] In catchment areas serving more than one county, the ratings for each county were totaled and then an average score was calculated.

[c] Score range = 0 to 255; 0-75 = Poor Long Term Care Service System; 76-150 - Fair Long Term Care System; 151-255 - Well Developed Long Term Care System.

Demonstration Service Providers

The ACCESS MAP project contracts with 53 agencies to provide services in the Monroe County area. VNS and MCHD were the primary "preferred provider" agencies, but contracts have been negotiated with 53 other service agencies in the Rochester area. In addition, the local chapter of the Alzheimer's Association was given a contract to provide on-going training for the ACCESS staff on Alzheimer's disease, working with Alzheimer's patients and their families, and provide other dementia specific training. For example, the Alzheimer's Association conducted a week long training session during the implementation phase of the project for ACCESS, and MCHD case managers, day care staff, and case aides, which involved the etiology of the disease and behavior patterns. Films, slides, workshops, and role playing were used during this training. In addition, the Alzheimer's Association is contracted to provide caregiver training sessions and conduct support groups for the project. The Alzheimer's staff meets once a month with ACCESS staff to discuss on-going training needs, and in-service training sessions are scheduled regularly.

The primary reasons for subcontracting were: the host agency did not offer the service; the client already had an ongoing relationship with another provider and did not want to change; the client lived in an area where the service is geographically more accessible through another provider; and many of the services had state regulatory requirements that precluded ACCESS from providing the service. Case managers were given a great deal of freedom in determining the appropriate service provider for each client. Generally, the demonstration project is matching each service provider's prevailing rate.

Even with a service rich area like Monroe County, there were some problems with obtaining needed services for clients. Overall, the biggest problem for the agency was scheduling personal care aid. Since the usual service allotment was for two hours, it was difficult to find aides willing to work just two hours for a client. ACCESS attempted to deal with this problem by scheduling an aide for four hours on one day rather than two hours a day for two days. It was unclear how well that was working. However, there were few other problems that occurred with the contract agencies.

Services provided by ACCESS include:

- case management/service coordination

Services subcontracted for include:

- adaptive equipment - cognitive/physical
- chore services - general/repairs & maintenance
- companion services (including companion training)
- consumable care goods
- adult day care

- family counseling
- home health aide
- housekeeping
- medical assessment
- mental health service counseling
- medical supplies
- personal care aides
- transportation - client/caregiver
- skilled nursing

Outreach and Enrollment

Program Census

The catchment area served by ACCESS includes Monroe County, situated on the north-central part of upstate New York. Monroe County includes the city of Rochester as well as suburban and rural areas. The population of Monroe County is about 725,000, of whom approximately 80,000 are noninstitutionalized elderly. Assuming that 4 percent of the noninstitutionalized elderly have Alzheimer's disease or related dementia, approximately 3,200 demented Monroe County residents living at home were eligible for the demonstration. The site assumed that 50 percent of those 3,200 elderly residents would be referred to the demonstration and that 50 percent of the 1,600 referred applicants would agree to participate. Furthermore, the site assumed a 15 percent drop-out rate, leaving 680 persons eligible to participate in the demonstration.

The population of Monroe county in 1980 was predominantly White and relatively wealthy with a median household income of over $20,000 and a per capita income of over $8,000 annually. Eighty-eight percent of the population lived within an urban catchment area. Eighty percent of the population of Monroe County were White, 10 percent were Black, 2 percent were Hispanic, and 8 percent were Other. Almost 9 percent of Monroe County resident lived below the poverty level in 1980.

In 1980, the aged made up 11 percent of the population. By 1985, the elderly population had increased to 85,157 residents, or 11.9 percent of the population with 5 percent of the elderly 75 or older and approximately 1 percent over the age of 85. The majority of those over age 65 are White (97 percent) and female (62 percent). Three-quarters of the elderly had incomes below $10,000 and 7.4 percent of the elderly were below the federal definition of the poverty level.

ACCESS originally proposed to enroll 540 participants (270 in the treatment and 270 in the control group). However, after the award, the ACCESS program increased its numbers to 300 treatment and 300 control participants. Later in the client enrollment buildup phase (April 1991), the ACCESS MAP raised the census goals for the program to 800 cases (400 treatment and 400 control). Each demonstration site was required to match the treatment client census with an equal number of control group clients. The treatment/control group issues are discussed in the research design section of this report.

A total of 670 clients had applied to the program by April 1991; 134 clients, or 20 percent of total client applicants, had attrited due to institutionalization or death or had moved out of the demonstration's catchment area by April 30, 1991. On April 30, 1991, the New York demonstration site had 536 clients enrolled; 263 treatment clients and 273 control clients.

Difficulties Encountered Reaching Enrollment Goals

Enrollment in the program was slow for a variety of reasons, including (1) the variety of long term care service programs available to Monroe County residents; (2) the generous Medicaid programs in the county as well as the Alzheimer's-specific programs; (3) denial on the part of the caregiver or family about the seriousness of the situation; (4) a reluctance on the part of the caregiver to accept services or to have a stranger in the house because it might upset the patient; (5) reluctance on the part of service providers to refer clients due to turf protection; (6) Alzheimer's victims who do not have a caregiver and thus are unable to access the system, (7) Rochester is an "over-researched community" and many Alzheimer's families are "tired of being enrolled into studies (e.g., drug studies) and ending up in the control group," and (8) physicians not knowing enough about the program to refer clients.

Table NY-3 shows the number and proportion of cases who terminated during the application process and the reason for termination by quarter through April 1991. The primary reasons for termination were that these clients: had an ineligible diagnosis (37 percent); had been institutionalized between the time of application and case management assessment (30 percent); had died (7 percent), were found to be in a similar case management system (6 percent); refused to comply with demonstration requirements (5 percent); lived outside the demonstration's catchment area; (4 percent) or refused to sign the consent form (4 percent).

In response to the lower-than-expected enrollment rate, the Rochester site expanded its catchment area into four rural counties surrounding Monroe County. These counties have less developed service delivery systems than the one in Monroe County but similar proportions of elderly as Monroe County. It was expected that this expansion of the catchment area would enable the New York site to reach its enrollment goal of 800 clients by October 1991 when the enrollment build-up period of the project ended.

Case Management Services

Compliance with the Case Management Model

The Case Management model is one of the primary interventions being tested under the demonstration. To help ensure that each site maintained the appropriate

Table NY-3

Medicare Alzheimer's Project: New York
Reason for Termination During the Application Process by Quarter
(January 1990 through June 1991)

REASON	1990								1991				TOTAL	
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Outside of Catchment Area					2	8					2	13	4	4
Ineligible Diagnosis			2	18	8	32	18	55	5	25	9	60	42	37
Did Not Have Medicare Part A and Part B					2	8	1	3					3	3
Unwilling to Consider Co-Payment							2	6					2	2
Refused to Sign Consent Form	1	11	1	9			2	6					4	4
Refused to Accept Possibility of Control Group Assignment			1	9									1	-1
Found to be in Case Managed/ Duplicate Provider System	2	22	3	27	1	4			1	5			7	6
Refused to Comply with Demonstration Requirements[a]			1	9	2	8			2	10	1	7	6	5
Institutionalized	6	67	1	9	10	40	8	24	8	40	1	7	34	30
Died			2	18			2	6	3	15	1	7	8	7
Physician Failed to Return Physician Form									1	5			1	-1
Could Not Locate for Intake Interview														
Duplicate Applicant														
Not Interested[b]											1	7	1	-1
TOTAL[c]	9	100	11	99	25	100	33	100	20	100	15	101	113	100

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] e.g., intake interview, follow-up interviews, case management.

[b] The two primary reasons reported under the "not interested" category were the client's family members could not all agree about participation or the potential client did not want to be in the project.

[c] Percentages greater than or less than 100 due to rounding.

case manager-to-client ratio during the evaluation's caseload build-up phase (December 1989 - March 1991), the sites were required to provide monthly reports on the amount of time each case manager was spending on case management-related activities and the number of active cases for each case manager. With this information, it was possible to monitor the case manager-to-client ratio to determine if the project was complying with the Model A criteria of one case manager per 100 clients. The sites were allowed a 5 percent variance above or below the case manager-to-client ratio during the caseload build-up phase due to addition of clients, transitions in cases, addition of staff, etc. For the Model A sites, this variance could range from 95 to 105 active cases per case manager and not be out of compliance with the Model A criteria.

To be in compliance with the 1:100 case management model in the Model A sites, the case managers should be spending, on average, between 1 to 1 1/2 hours per month per active client. The data in Table NY-4 show that, during the client build-up phase, the New York site fluctuated radically from a low of 1 case manager to 24 clients in February 1990 to a high of 1 case manager to 144 clients in March 1991. Overall, the New York site did not reach compliance with the Model A criteria until December 1990 and fell under the allowable low end to 1:85 in May 1991. Based on the data in Table NY-4, the case managers in New York were spending slightly more than the allotted 1 to 1 1/2 hours per month per client by the end of the caseload build-up phase.

Case Management Activities

Table NY-5 shows a distribution of case management time among a variety of activities. As can be seen in the table, case managers were spending almost a third of their time in service monitoring/follow-up activities (28 percent). Approximately 19 percent of the case managers' time was spent in the initial assessment of the client while 17 percent of their time was spent in record keeping/data entry activities. Initial care planning and service arrangement activities were the next most frequent with 9 percent of case managers time spent in that activity. Eight percent of case managers' time was spent in travel while 3 percent of time was spent in each of the following outreach and intake activities: caregiver education and training activities and administrative/supervisory meetings.

Demonstration Service Utilization Patterns

During the caseload build-up phase of the demonstration, the number of active clients rose steadily at the New York site. As shown in Table NY-6, by the second quarter of 1991, the New York site averaged 284 clients per month. Of particular interest is the relatively high proportion of clients receiving case management services only during the fourth quarter of 1990 and the first two quarters of 1991 (18 percent, 35 percent, and 32 percent respectively). For those clients and their caregivers, there were no direct services being provided other than case

Table NY-4

Medicare Alzheimer's Project: New York
Compliance with the Model A Case Manager-to-Client Ratio of 1:100*

Month	Case Manager-to-Client Ratio[a]
February 1990	1:24
March 1990	1:41
April 1990	1:69
May 1990	1:47
June 1990	1:57
July 1990	1:73
August 1990	1:62
September 1990	1:78
October 1990	1:73
November 1990	1:55
December 1990	1:107
January 1991	1:101
February 1991	1:122
March 1991	1:144
April 1991	1:97
May 1991	1:85
June 1991	1:95

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] The average case manager-to-client ratio was derived by dividing the total hours each case manager spends on case management activities each month by the number of clients assigned to the case managers that month. The average hours spent per case-managed client were then converted to a ratio by dividing the number of hours per client by the total hours worked in an average month (i.e., 168 hours). In the Model B projects, with a 1:100 case manager to client ratio, each client should receive approximately 1.5 hours of case management per month.

* The sites were allowed a 5% variance above or below the client-to-case manager ratio during the caseload build-up phase due to additions of clients, transitions of cases, additions of staff, etc. For the Model A sites, this variance could range from 95 to 105 clients per case manager and not be out of compliance with the Model A criteria.

Table NY-5

Medicare Alzheimer's Disease Demonstration: New York Case Management Activities

Activity	Percent Time Spent in Each Activity[a]
Outreach and Intake	3
Initial Assessment	19
Initial Care Planning/Service Arrangement and Costing of Care Plan	9
Case Conferences	3
Service Monitoring/Follow-up	28
Caregiver Education and Training	3
Public Relations	1
Administrative/Supervisory Meetings, Reports	3
Record Keeping/Data Entry	17
Local Travel	8
Other	6
TOTAL	100

[a] Each case manager completed a time study allocating the total number of hours typically spent during a week in various activities. The Time Study was completed in the summer of 1990, during the caseload build-up phase of the demonstration.

management. The percentages for case management only ranged from a low of 8 percent in the first quarter of 1990 to a high of 35 percent during the first quarter of 1991.

The case managers have identified several factors that impact service utilization patterns. Some of the client's were newly diagnosed and did not, as yet, require additional services. In some cases, there was a discrepancy between what the client/caregiver think they need and what the case manager and or the demonstration have to offer. For example, the case manager may feel that adult day care services would be the best service (or in locations where a variety of services options may not be available, the ONLY service) for the client but the caregiver is not willing to be separated from the client (or vice versa) or the caregiver is unable to get the client to the program (or even able to have the client ready to go when the program can provide transportation). Thus, the effort required of the caregiver to get the client "ready" for the service may outweigh the potential benefits. However, this did not seem to be the case for the ACCESS program where over 25 percent of the direct services provided to clients was Adult Day Care services. Finally, reluctance to accept services has also impacted utilization. Many families may decline services due to the stigma attached to Alzheimer's disease or because the client becomes too agitated when strangers enter the house.

Table NY-6

Medicare Alzheimer's Project: New York
Services Use Patterns by Quarter
(March 1990 through June 1991)

Service Use	1990								1991			
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Average Number Active Treatment Clients per Month	40	100	79	100	131	100	213	100	269	100	284	100
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	34	85	73	92	121	92	160	75	162	60	187	66
Average Number Treatment Clients Receiving Case Management Only	3	8	2	3	6	5	38	18	95	35	91	32
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	3	8	4	5	4	3	15	7	12	5	6	2

PORTLAND, OREGON - GOOD SAMARITAN HOSPITAL AND MEDICAL CENTER

History and Sponsorship

The Medicare Alzheimer's Disease Demonstration Project in Portland, Oregon is sponsored by Good Samaritan Hospital and Medical Center (GSH&MC), a major medical center in the Pacific northwest. GSH&MC is part of Legacy Health Systems, which operates five hospitals and a home health agency in the greater Portland area. GSH&MC has extensive experience with community-based long term care having made a commitment in the late 1980's to offer a full spectrum of health and support services to chronically ill and frail patients and their families through its Departments of Neurology and Medicine. GSH&MC has organized and developed in-home care, respite care, hospice, family support services, assessment clinics, and continuing care services. Its Alzheimer's Assessment Clinic, which has been in operation for over six years, provides an interdisciplinary evaluation including an in-home assessment, examinations by a neurologist or an internist as well as a psychologist, and laboratory testing which is followed by a family conference. GSH&MC also operates two long-term care facilities, one with a special Alzheimer's unit.

GSH&MC is also a participating institution in the Alzheimer's Disease Center of Oregon (ADCO). ADCO is a regional Alzheimer's "center without walls" and includes the Portland Veterans Administration Medical Center, Oregon Health Sciences University, and state chapters of the Alzheimer's Association. The center is dedicated to improving the quality of care for Alzheimer's patients and families through advocacy, medical and behavioral research and education.

During the first year of the demonstration project, GSH&MC in conjunction with Oregon Health Sciences University and the Portland Veterans Administration Medical Center applied for, and was designated by the National Institute on Aging as, an Alzheimer's Disease Research Center. The center performs basic science and bio-medical research but has no health services interventions.

GSH&MC's interest in the demonstration project was a natural extension of its previous commitment to serving Alzheimer's patients and their families. GSH&MC had found that, despite the prevalence of Alzheimer's disease and related disorders, victims of dementia were seldom singled out for case-managed community-based care demonstrations. More often, these individuals had been minimally included in larger groups of the physically impaired or mentally ill. GSH&MC felt that such general and unstratified groups have failed to recognize the unique characteristics of Alzheimer's patients whose care requires medical and functional management as well as the maintenance of the family support system. Furthermore, while the Portland area is generally considered to be resource rich in terms of community-based services such as adult day health, support groups, and home care, these services are often expensive and uncoordinated. GSH&MC's

experience has been that families of Alzheimer's victims tend to seek services too late or not at all.

GSH&MC's objective in applying for the demonstration project was to develop a coordinated care system that: (1) links the family with needed services and maintains its ability and commitment to care for the Alzheimer's patient; 2) integrates health and social services into a cohesive system; 3) empowers families in the management process of the disease; 4) improves quality of care for the Alzheimer's clients; and 5) facilitates communication and networking within the formal support system.

Intraorganizational Structure

The program operates out of one of the buildings in the GSH&MC complex, which houses the key program staff including: the MAP project director; the clinical operations manager (who is responsible for supervising the case managers and service delivery component of the project); the case managers, the intake workers, and support staff. On the project part-time were two members of GSH&MC who filled project-specific roles--a planner and a financial accountant. The project and the staff were guided by a Technical Advisory Committee, which was composed of members of the medical and social service provider community as well as researchers from the University. Figure OR-1 is a chart identifying overall responsibility for performance of key project functions.

Program Staffing

Table OR-1 shows the demonstration programs staffing pattern at the end of the caseload build-up phase of the project on April 30, 1991, when the project had 303 active treatment group clients. The demonstration project had 2.4 FTE performing administrative and financial activities including: the Project Director, the Clinical Operations Manager, the Financial Accountant, and the Planner. There were 4.1 FTE staff conducting outreach and intake activities. There were 3.3 FTE case managers responsible for client assessment, care planning and follow-up services. The Clinical Operations Manager spent .2 FTE staff hours conducting education and training for the staff. There were also 2.2 FTE research assistants who assisted the case managers, and 3.7 FTE support staff who performed primarily clerical activities.

Staff Experience

The key administrative staff on the project all had strong backgrounds in community-based services for the elderly. The project director had extensive experience in health care and grants management. The clinical operations manager also had extensive experience directing case management operations in community long term care programs. The planner had a long history of grant writing and program development for many of GSH&MC's special programs.

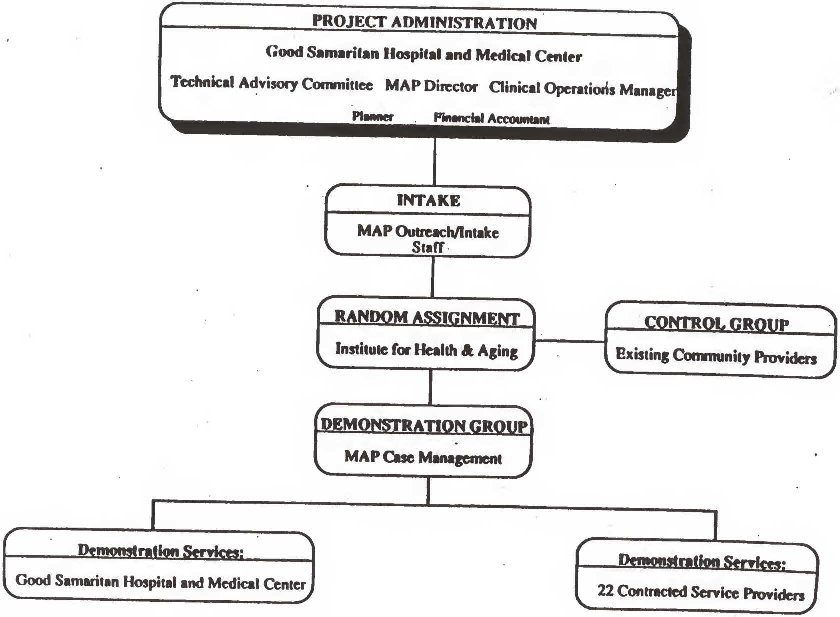
Table OR-1

Medicare Alzheimer's Project: Oregon Demonstration Staffing Patterns

Functional Activities	(Full-Time Equivalent Staff) (April 1991)
Administrative/Finance	2.4
Outreach/Intake	4.1
Case Management	3.3
Education/Training	.2
Research Assistant/Case Aide	2.2
Support Staff	3.7
TOTAL STAFF	15.9

Figure OR-1

Medicare Alzheimer's Project: Oregon
Responsibilities for Primary Project Functions


PROJECT ADMINISTRATION
Good Samaritan Hospital and Medical Center
Technical Advisory Committee
MAP Director
Clinical Operations Manager
Planner
Financial Accountant
INTAKE
MAP Outreach/Intake Staff
RANDOM ASSIGNMENT
Institute for Health & Aging
CONTROL GROUP
Existing Community Providers
DEMONSTRATION GROUP
MAP Case Management
Demonstration Services:
Good Samaritan Hospital and Medical Center
Demonstration Services:
22 Contracted Service Providers

The case management staff was composed of individuals who had Bachelor's degrees in nursing or social work and had at least one year of experience providing case management and working with the frail elderly and/or dementia patients. The intake staff were also experienced social workers with a number of years of experience working in community-based health care settings.

Service Environment

The Community Long Term Care Service System

Oregon's Senior Services Division manages all of the state's community and institutional care for the elderly including Medicaid, a home and community-based services waiver program, a state-funded home services program, and the Older Americans Act. The Area Agencies on Aging administer the programs locally. In general, the greater Portland area is usually thought to be resource rich with a broad array of community-based services available including a rich array of housing arrangements ranging from housing with minimal services to nursing care in non-institutional settings.

Table OR-2 summarizes the catchment area service systems by scoring community based services according to their availability, accessibility and quality of care. The scores represent an average based on the opinions of knowledgeable spokespersons from the service provider community. The overall score for the service provider system within the MAP project's catchment area was relatively high–161 out of a possible score of 225 suggesting a well developed long term care system. Some services, however, were reportedly not very accessible or of low quality.

Integrative services including case management, geriatric assessment, and information and referral received fairly high service scores. Home care services were rated fairly high with the exception of home health aides, where the quality of care has been problematic for a number of years. Home support services were rated in the mid-range with some shortage of services reported for mental health counseling and transportation. In contrast special purpose services were rated fairly high. Similarly, living arrangements including various types of supportive housing for the elderly were rated fairly high with respect to availability, accessibility and quality. Compared to the other demonstration sites, the Portland catchment area offered a much broader range of assisted/supportive housing and a number of the demonstration clients resided in some type of special housing.

Services Provider Contracts

Although GSH&MC has within the organization the capability of providing most of the services offered by the demonstration program, it is not the principal service provider for demonstration clients primarily because of the broad catchment area served by the demonstration. The only two services which GSH&MC provides directly are companion and companion for caregiver education and training.

Table OR-2

Medicare Alzheimer's Project: Oregon
Community Spokesperson's Ratings on the Availability, Accessibility, and Quality of the Long Term Care Service System

Service Type	Maximum Points[a]	Catchment Area Score[b]
Integrative Services		
Case Management		6
Geriatric Assessment		9
Information and Referral		7
Subtotal Points	27	22
Home Health Care		
Skilled Nursing		7
Therapies		7
Social Services		7
Home Health Aides		5
Subtotal Points	36	26
Home Support Services		
Homemaker/Chore Services		6
Personal Care Services		6
Meals (home & community)		7
Adult Protective Services		6
Mental Health Counseling		5
Transportation		5
Subtotal Points	54	35
Special Purpose Services		
Hospice Care		8
Day Health Care		7
Social Day Care		7
Respite Care		6
Training for Informal Caregivers		6
Support Services for Informal Caregivers		6
Subtotal Points	54	40
Living Arrangements		
Senior Citizens Housing		6
Congregate Housing		6
Board and Care/Residential Care		7
Foster Care		7
Intermediate Care Facility		7
Skilled Nursing Facility		5
Subtotal Points	54	38
TOTAL POINTS[c]	225	161

[a] Each service type was ranked on a scale of 0 to 3 on the dimensions of availability (0=None, 1=Low, 2=Medium, 3=High), accessibility (0=None, 1=Low, 2=Medium, 3=High), and quality (0=None, 1=Low, 2=Medium, 3=High). The service score for each service type could range from 0 to 9. The maximum service points within service subgroups and the total possible points across all long-term care services within a catchment area are shown in column 2.

[b] In catchment areas serving more than one county, the ratings for each county were totaled and then an average score was calculated.

[c] Score range = 0 to 255; 0-75 = Poor Long Term Care Service System; 76-150 - Fair Long Term Care System; 151-255 - Well Developed Long Term Care System.

Beyond this, all other demonstration services are contracted out to 22 service provider agencies. The number of contracted service providers by type of service were:

Service	Number of Contracts
In-home Services	7
Adult Day Care	4
Equipment/Supplies	2
Mental Health Counseling	3
Transportation	2
Education/Support	4

Outreach and Enrollment

Program Census

The catchment area served by the demonstration project encompasses all of Multnomah, Washington, and Clackamas counties and portions of Columbia County. The catchment area was selected to include both urban and rural areas in order to provide the project with greater opportunity to test outreach strategies and service delivery systems.

For the demonstration, the client caseload was calculated by basing treatment group distribution on population statistics. In 1987, the population over 65 years of age in each of the catchment areas was: Multnomah County 81,442; Washington County 25,187; Clackamas County 28,070; and Columbia County 2,840. Using national estimates that 15 percent of the elderly over the age of 65 have dementia and 85 percent of this number are cared for in the community, it was projected that there would be 17,838 eligible participants for the demonstration project.

Oregon's initial project census was 600 (300 treatment group clients and 300 control group members). The project was able to meet its original goal by April 30, 1991. On that date, there were 303 active treatment group clients.

Difficulties Encountered Reaching Enrollment Goals

While the Oregon demonstration project was able to obtain its projected number of study members, there were periods of time during the caseload build-up phase of the project when program census lagged well behind the original projections. Despite a well organized outreach plan from the outset of the demonstration, the project found it much harder to locate and enroll clients than originally anticipated.

The major reason cited for the lower rate of enrollment than projected was fewer than anticipated referrals from familiar sources including physicians within GSH&MC, the Family Support Center at GSH&MC, the Alzheimer's Association chapters in the catchment area, and the four Area Agencies on Aging in the catchment area. Referrals from these sources did increase slightly over time, but they never reached the projected levels. Over time, the project also found the need to have a well-developed outreach and marketing plan. The initial outreach plan was not a multi-faceted approach because the project also did not expect to need to place so much emphasis on outreach. Like a number of the other sites, the Oregon project was caught off guard by the need to find clients and encourage them to become a part of the project.

Table OR-3 shows the number and proportion of cases who terminated during the application process and the reason for termination by quarter. The major reasons for noncompletion of the application process have been fairly consistent over time. Approximately one third (33 percent) of the applicants were terminated because the applicant had an ineligible medical diagnosis. Another third of the applicants (32 percent) were permanently placed in a nursing home between the time the Application Form was requested and a follow-up call was made by Intake Workers (generally not more than a two week period). Other less frequent reasons for noncompletion of the application process were: the applicant was already receiving services from another service provider which effectively duplicated the demonstration services (9 percent); the applicant lived outside the demonstration's geographic catchment area (7 percent); the applicant did not have Medicare Part A and/or Part B coverage which was a demonstration requirement (9 percent); the client died before the application process was complete (6 percent); and the family and/or client was not interested in applying after receiving the application packet (6 percent).

At the end of June 1991, there had been a total of 912 application requests for the demonstration; of these applications 140 were not completed. Overall, 15 percent of the potential applicants who applied for the demonstration were found to be ineligible based on the demonstration's eligibility criteria, or in a very small proportion of the cases, the applicant was not interested.

Another factor that had an impact on caseload build-up was attrition from the study due to death, permanent institutionalization, refusal to continue to participate in the project, etc. At the end of the caseload build-up phase of the project on April 30, 1991, 14 percent of the original clients had already attrited from the study primarily due to institutionalization and death. Although the proportion of clients who had attrited was within the original projections, it still required additional effort to conduct outreach and intake for new clients.

Table OR-3

Medicare Alzheimer's Project: Oregon
Reason for Termination During the Application Process by Quarter
(January 1990 through June 1991)

REASON	1990								1991				TOTAL	
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Outside of Catchment Area			1	8			2	7	2	3	5	17	10	7
Ineligible Diagnosis	1	25	3	25	1	20	16	55	19	31	7	24	47	33
Did Not Have Medicare Part A and Part B	1	25	1	8			4	14	3	5	1	3	10	7
Unwilling to Consider Co-Payment														
Refused to Sign Consent Form														
Refused to Accept Possibility of Control Group Assignment														
Found to be in Case Managed/ Duplicate Provider System			1	8			2	7	7	11	2	7	12	9
Refused to Comply with Demonstration Requirements[a]														
Institutionalized	2	50	3	25	3	60	2	7	25	41	10	35	45	32
Died			3	25					3	5	2	7	8	6
Physician Failed to Return Physician Form														
Could Not Locate for Intake Interview														
Duplicate Applicant														
Not Interested[b]					1	20	3	10	2	3	2	7	8	6
TOTAL[c]	4	100	12	99	5	100	29	100	61	99[c]	29	100	140	100

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] e.g., intake interview, follow-up interviews, case management.

[b] The two primary reasons reported under the "not interested" category were the client's family members could not all agree about participation or the potential client did not want to be in the project.

[c] Percentages greater than or less than 100 due to rounding.

Case Management Services

Compliance with the Case Management Model

Two case management models are being tested under this demonstration project: Model A sites were to maintain a case manager-to-client ratio of 1:100; Model B sites were to maintain a case manager-to-client ratio of 1:30. Oregon was a Model A site. To help ensure that each site maintained the appropriate case manager-to-client ratio during the caseload build-up phase of the demonstration, the sites were required to provide monthly reports to HCFA on the amount of time each case manager was spending on case management activities and the number of active cases assigned to each case manager. With this information it was possible to monitor the case manager-to-client ratio to determine if the project was complying with the Model A criteria of one case manager to 100 clients.

As the data in Table OR-4 shows, it took the Oregon project a full year to reach its case management ratio. Then, in February of 1991, the case manager-to-client ratio had become somewhat higher than the model guidelines (with the exception of the month of May), which indicates that, on average, the case manager was able to spend slightly less time case managing each client than specified in the model. However, it should be noted that sites were permitted a 5 percent variance over or under their specified case manager-to-client ratio each month in Model A sites (95-105 clients). Since the Oregon staff had two full-time and two part-time case managers, they were potentially able to minimize the impact of having a slightly higher ratio of clients per case manager than specified in the model.

Case Management Activities

Case managers at the Oregon project were spending the majority of their time in four activities (see Table OR-5). The initial baseline assessment, which included a home visit, utilized 12 percent of the case managers' total time. Following the [redacted] velopment of the initial care plan, arranging for the services to ng out the care plan required an additional 15 percent of the me. Once the care plan was in place, service monitoring and basis consumed 29 percent of the case managers' time— ctivity in which the largest proportion of time was spent. Smaller proportions of the case managers time were spent on administrative/ supervisory meetings (16 percent); local travel (6 percent); outreach and intake (6 percent); and case conferences (6 percent).

Service Utilization Patterns

During the caseload build-up phase of the demonstration, the number of active clients was fairly low during the first three quarters. Then as outreach efforts were intensified and general community awareness about the demonstration project increased, enrollments increased quite substantially after October of 1990—almost

Table OR-4

Medicare Alzheimer's Project: Oregon
Compliance with the Model A Case Manager-to-Client Ratio of 1:100[*]

Month	Case Manager-to-Client Ratio[a]
February 1990	1:28
March 1990	1:36
April 1990	1:41
May 1990	1:30
June 1990	1:59
July 1990	1:66
August 1990	1:46
September 1990	1:72
October 1990	1:67
November 1990	1:88
December 1990	1:68
January 1991	1:97
February 1991	1:123
March 1991	1:137
April 1991	1:109
May 1991	1:101
June 1991	1:120

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] The average case manager-to-client ratio was derived by dividing the total hours each case manager spends on case management activities each month by the number of clients assigned to the case managers that month. The average hours spent per case managed client were then converted to a ratio by dividing the number of hours per client by the total hours worked in an average month (i.e.,168 hours). In the Model A projects, with a 1:100 case manager-to-client ratio, each client should receive approximately 1.5 hours of case management per month.

[*] The sites were allowed a 5% variance above or below the case manager-to-client ratio during the caseload build-up phase due to additions of clients, transitions of cases, additions of staff, etc. For the Model A sites, this variance could range from 95 to 105 clients per case manager and not be out of compliance with the Model A criteria.

Table OR-5

Medicare Alzheimer's Disease Demonstration: Oregon Case Management Activities

Activity	Percent Time Spent in Each Activity[a]
Outreach and Intake	8
Initial Assessment	12
Initial Care Planning/Service Arrangement and Costing of Care Plan	15
Case Conferences	6
Service Monitoring/Follow-up	29
Caregiver Education and Training	0
Public Relations	0
Administrative/Supervisory Meetings, Reports	16
Record Keeping/Data Entry	0
Local Travel	8
Other	6[b]
TOTAL	100

[a] Each case manager completed a time study allocating the total number of hours typically spent during a week in various activities. The Time Study was completed in the Summer of 1990, during the case load build-up phase of the demonstration.

[b] Time spent in case management training, principally reading resource materials.

one year after the demonstration began enrollment. As shown in Table OR-6, the initial enrollment was low, followed by increased enrollment of clients beginning in October 1990. By the second quarter of 1991, the demonstration project had on average 320 active treatment clients per month.

Throughout the caseload build-up phase of the demonstration, approximately three-fourths of the treatment clients were receiving both case management and demonstration services. During the second quarter of 1991, the proportion of clients receiving both case management and demonstration services increased to 82 percent. Compared to the other demonstration sites, Oregon had a high proportion of clients using demonstration services.

Table OR-6

Medicare Alzheimer's Project: Oregon
Services Use Patterns by Quarter
(March 1990 through June 1991)

Service Use	1990								1991			
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Average Number Active Treatment Clients per Month	62	100	98	100	130	100	201	100	264	100	320	100
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	47	75	75	77	101	77	147	73	191	72	263	82
Average Number Treatment Clients Receiving Case Management Only	6	10	17	17	24	18	44	22	49	19	36	11
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	9	14	6	6	5	5	10	5	24	9	20	6

MEMPHIS, TENNESSEE - NORTHEAST COMMUNITY MENTAL HEALTH CENTER

History and Sponsorship

The Alzheimer's Consortium, which sponsors the Medicare Alzheimer's Disease Demonstration, is comprised of 17 health and social service providers serving a four-county area in southwest Tennessee. These agencies, under the leadership of the Delta Area Agency on Aging (DAAA), had worked together in various combinations on past projects. For the demonstration, the agencies' strengths, experiences, and resources were brought together to address a commonly perceived lack of services specifically targeted to Alzheimer's victims and their families. Collectively, the consortium is a unification of urban and rural efforts, bringing together as one unit the agencies which provide the vast majority of all services delivered to elderly persons in the catchment area.

The Northeast Community Mental Health Center (NECMHC) was chosen as the lead agency by the consortium members based on its previous experience in grantsmanship and its experience with the target population for the demonstration. NECMHC is a fully licensed community mental health center providing a wide range of mental health services to a catchment area of approximately 200,000 individuals. The Center has an extensive geriatric program, with approximately 300 clients regularly seen for counseling. In addition to NECMHC, four other key participants in the consortium provide services to demonstration project clients.

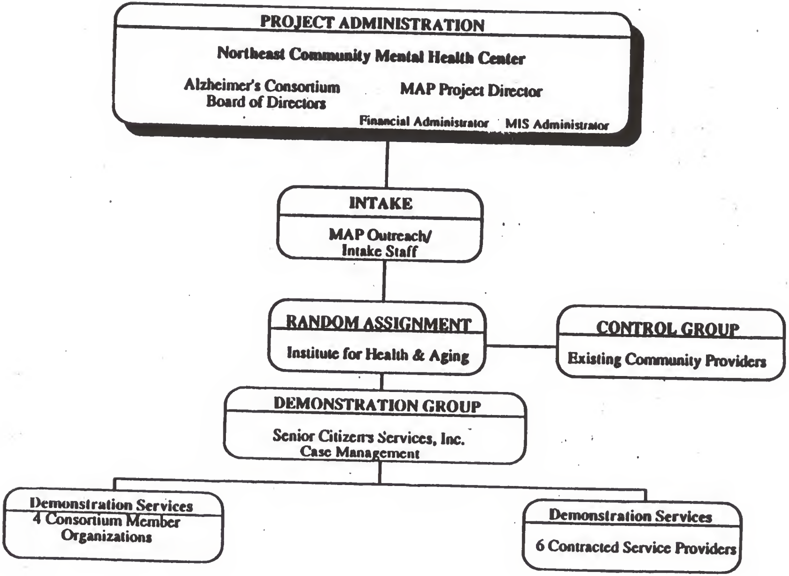
Alzheimer's Day Care is a nationally recognized program formed in 1983 in Memphis providing a day care and respite program for up to 50 Alzheimer's victims and their families. Alzheimer's Day Care, which combines extensive work by volunteers from Alzheimer's families with professional staff, is a unique public-private partnership with the City of Memphis.

The Memphis Area Chapter of the AA serves a five-county area in west Tennessee including the initial four county demonstration catchment area. The Memphis chapter organizes and trains local professionals, provides information to the public about service availability, supports legislation to help the target population, and works closely with local mental health centers and nursing homes providing services to Alzheimer's victims.

Metropolitan Inter-Faith Association (MIFA) is an ecumenical non-profit agency which sponsors 27 programs directed towards providing volunteer coordination, self-help for the able, support services for the frail, and emergency services for those in crises. More than half of MIFA's programs include services for the elderly. Within the demonstration catchment area, MIFA provided extensive services in three areas: transportation services, meals on wheels, and congregate meals.

Figure TN-1

Medicare Alzheimer's Project: Tennessee
Responsibilities for Primary Project Functions


PROJECT ADMINISTRATION
Northeast Community Mental Health Center
Alzheimer's Consortium Board of Directors
MAP Project Director
Financial Administrator
MIS Administrator
INTAKE
MAP Outreach/ Intake Staff
RANDOM ASSIGNMENT
Institute for Health & Aging
CONTROL GROUP
Existing Community Providers
DEMONSTRATION GROUP
Senior Citizens Services, Inc. Case Management
Demonstration Services
4 Consortium Member Organizations
Demonstration Services
6 Contracted Service Providers

Senior Citizens Services (SCS) is a non-profit social service agency with an emphasis on programs designed to delay institutionalization and promote independence. SCS operates the state Medicaid waiver program (Home Care Option for Medicaid Eligibles) and has conducted other demonstration projects which has given the organization considerable experience with different types of case management models. The case management component of the demonstration project is subcontracted from SCS.

Other consortium agencies who participated in the planning process for the demonstration and continue to serve on the Consortium Board of Directors in an advisory capacity include: City Of Memphis Government; Shelby County Government; DAAA; Frayser-Millington Mental Health Center; Midtown Mental Health Center; Southeast Mental Health Center; Tri-County Mental Health Services; Whitehaven-Southwest Mental Health Center; Alverno-Memphis Corporation (which operates a certified home health agency); Veterans Administration Medical Center; University of Tennessee College of Social Work; and University of Tennessee Division of Geriatrics-Gerontology.

Intraorganizational Structure

The demonstration project is located in a small commercial office on the outskirts of Memphis and houses key program staff including the MAP project director, the financial administrator, the MIS administrator, and the intake staff. The case management staff, including the case management supervisor, maintain their offices at SCS, the agency which the MAP project subcontracts with for case management services. The decision to have case management staff offices at SCS rather than in the MAP demonstration project offices reflected the MAP project director's desire for the case managers to have access to, and develop working relationships with, the large case management staff at SCS who had already developed extensive community networks on other projects. Figure TN-1 is a chart identifying overall responsibility for performance of key project functions.

Program Staffing

Table TN-1 shows the demonstration project's staffing pattern at the end of April 1991 when the program reached its original enrollment goal. There were 1.5 FTE administrative and financial oversight staff members including: the project director, the finance/billing administrator; and the case management supervisor. There were 3.25 FTE staff members responsible for outreach and intake activities. There were 3.05 FTE staff performing the case management activities including three full-time case managers and the case management supervisor who spent 5 percent of her time directly managing a small number of clients. Education and training were the responsibility of one part time (.65 FTE) family education coordinator who was assisted by the project director (.10 FTE) and the case management supervisor (.05 FTE). There were two FTE staff who served as case aides to the case managers.

Table TN-1

Medicare Alzheimer's Project: Tennessee Demonstration Staffing Patterns

Functional Activities	(Full-Time Equivalent Staff) (April 1991)
Administrative/Finance	1.55
Outreach/Intake	3.25
Case Management	3.05
Education/Training	.65
Research Assistant/Case Aide	2.00
Support Staff	3.00
TOTAL STAFF	12.50

Finally, there were two FTE support staff—an administrative assistant and an MIS operator. In total, the project employed 12.50 FTE staff.

Staff Experience

The project director and the case managers all had extensive experience in community-based services for the elderly. The case management supervisor also had previous experience working with individuals with dementia. Beyond this, the majority of the other staff had no formal background or experience working with the elderly and/or dementia patients. Ongoing staff education and training was an important part of the program during the caseload build-up phase of the project.

Service Environment

The Community Long Term Care Service System

The catchment area is the Memphis Delta Planning and Service Area in the southwest corner of Tennessee, encompassing one large urban and three rural counties. Shelby County includes all of the greater Memphis metropolitan area and has a population of well over a million people with a wide range of medical, human, and social services available within close proximity. The three surrounding counties in the catchment area (Lauderdale, Tipton and Fayette counties) are almost exclusively rural in nature with a much more limited pattern of services and health resources available.

Table TN-2 summarizes the characteristics of the long term care system within the demonstration project's urban (Shelby) and rural (Lauderdale, Tipton and Fayette) counties. The scores represent the ratings of knowledgeable spokespersons in each of the areas who rated community-based services according to their availability, accessibility, and quality of care. The maximum score for a fully developed high quality long term care system would be 225. The total score for the urban catchment area (Shelby County) was 153 indicating a fairly well-developed long term care system. In contrast, the total score for the three rural counties was only 103, which is on the low end of a "fair long term care system."

In both the urban and rural areas, integrative services including case management and geriatric assessment were reportedly not well developed. In the urban county, home health care services received relatively high ratings, but were less available and accessible in the rural counties. A similar pattern was reported for home support services with the rural counties having fewer services available especially transportation and homemaker/chore and personal care services. In both the urban and rural counties the service scores for special purpose services were relatively low. Notably, none of the counties had any day health care available and the rural counties also had no hospice or social day care.

Table IV.2

Medicare Alzheimer's Project: Tennessee

Community Spokesperson's Ratings on the Availability, Accessibility, and Quality of the Long Term Care Service System

Service Type	Maximum Points[a]	Catchment Area Scores[b]	
		Shelby County	Lauderdale, Tipton and Fayette Counties
Integrative Services			
Case Management		4	0
Geriatric Assessment		7	3
Information and Referral		8	3
Subtotal Points	27	19	6
Home Health Care			
Skilled Nursing		8	6
Therapies		8	5
Social Services		6	4
Home Health Aides		8	6
Subtotal Points	36	30	21
Home Support Services			
Homemaker/Chore Services		6	4
Personal Care Services		6	4
Meals (home & community)		8	6
Adult Protective Services		6	5
Mental Health Counseling		9	6
Transportation		6	3
Subtotal Points	54	41	28
Special Purpose Services			
Hospice Care		6	0
Day Health Care		0	0
Social Day Care		4	0
Respite Care		5	4
Training for Informal Caregivers		6	6
Support Services for Informal Caregivers		8	6
Subtotal Points	54	29	16
Living Arrangements			
Senior Citizens Housing		8	4
Congregate Housing		6	4
Board and Care/Residential Care		7	6
Foster Care		0	0
Intermediate Care Facility		6	9
Skilled Nursing Facility		7	9
Subtotal Points	54	34	32
TOTAL POINTS[c]	225	153	103

[a] Each service type was ranked on a scale of 0 to 3 on the dimensions of availability (0=None, 1=Low, 2=Medium, 3=High), accessibility (0=None, 1=Low, 2=Medium, 3=High), and quality (0=None, 1=Low, 2=Medium, 3=High). The service score for each service type could range from 0 to 9. The maximum service points within service subgroups and the total possible points across all long-term care services within a catchment area are shown in column 2.

[b] In catchment areas serving more than one county, the ratings for each county were totaled and then an average score was calculated.

[c] Score range = 0 to 255; 0-75 = Poor Long Term Care Service System; 76-150 - Fair Long Term Care System; 151-255 - Well Developed Long Term Care System.

The urban and rural counties had quite different service scores with respect to specific types of living arrangements. The urban county's service score was higher for non-institutional types of housing (e.g., senior citizens housing, residential care) than for nursing facility care. In contrast, in the rural counties nursing home care (based on availability, accessibility and quality) was rated very high while other forms of housing were much less available, especially senior housing and congregate housing.

Demonstration Service Providers

As the program developed and the need for specific services became clear, there were four of the consortium member agencies that provided direct services to the treatment clients. The service provider consortium members and the services they provided are listed below.

Consortium Member	*Type of Service*
Alzheimer's Day Care	Day Care
Metropolitan Inter-Faith Association	Meals Transportation
Northeast Community Mental Health Center	Mental Health Counseling Family Counseling
Senior Citizens Services	Case Management Homemaker/Housekeeping

The majority of the services provided to the demonstration treatment clients were provided by non-consortium member agencies with whom the demonstration contracted for direct service provision. The contracted service providers and the services each agency provided for the demonstration are listed below.

Non-Consortium Member	*Type of Service*
Allied Medical	Adaptive Equipment Medical Supplies Medical Equipment Consumable Care Goods
Kirby Pines	Adult Day Care

Medical Personnel Pool	Skilled Nursing Home Health Aide Personal Care Housekeeping Companion
Partners for Service	Skilled Nursing Home Health Aide Personal Care Housekeeping Companion Adaptive Equipment Medical Supplies Medical Equipment Consumable Care Goods
ProCare	Home Health Aide Personal Care Housekeeping Companion
Trinity Health Care	Skilled Nursing Home Health Care Personal Care Companion

During the early phases of the demonstration, the project had considerable difficulty signing contracts with a sufficient number of home care agencies to meet the need for services. These provider problems, which largely reflected a shortage of adequately trained staff in the agencies, were resolved by the time the program reached steady-state.

Outreach and Enrollment

Program Census

The catchment area served by the consortium encompasses both urban and rural counties. Based on 1989 census data, population figures for the target counties were: Shelby County 777,113; Fayette County 25,930; Lauderdale County 24,555; and Tipton County 32,930; for a total of 859,903. With approximately 15.6 percent of the population of Tennessee 60 years of age and over, the estimated number of elderly in the catchment area were: Shelby 72,654; Fayette 3,222; Lauderdale 3,464; and Tipton 3,751. Although the total number of clients with Alzheimer's and related disorders that were served by consortium agencies in 1988 was only 535, the consortium felt this number was not reflective of the potential number of clients who could appropriately benefit from expanded availability of services in the catchment area.

The demonstration project proposed an original program census of 840 individuals (600 from the urban catchment area – 300 treatment group members and 300 control group members) and 240 from the rural catchment area (120 treatment group members and 120 control group members). This goal was subsequently revised (lowered by 240 clients) and the new census goal was set for 600 clients at the end of the caseload build-up phase on April 30, 1991. On that date, the demonstration had 597 active clients (301 treatment clients and 296 control group members), which was just three clients short of their census goal.

Difficulties Encountered Reaching Enrollment Goals

Although the Tennessee project eventually met its revised program census goals, it was not until the third quarter of the first year of the demonstration that the rate of client enrollment picked up and met original expectations. Several factors made it more difficult than anticipated to reach enrollment goals.

First, a waiting list of applicants who had telephoned the NECMHC when announcements about the forthcoming project were made in local newspaper was misplaced. Second, the original planners of the demonstration did not foresee the difficulties that project staff would have in identifying and enrolling eligible clients. Third, in the early phases of the demonstration, there seemed to be a reluctance on the part of the physician community to certify that individuals had Alzheimer's or one of the other eligible related dementias. It was not uncommon for the site to report that close to 100 application forms were waiting for the Physician Referral Form to be returned to the project verifying that the client had an eligible medical diagnosis. Other factors cited by staff as contributing to the lower than expected rate of enrollment were: initially many people in the community were just not aware of the project; other people were reluctant to inquire about the project for fear that it was too costly; and other people were reluctant to accept government help.

One major effort undertaken by the project to increase consumer awareness about the demonstration was to include a flyer about the demonstration in telephone bills. This particular mass advertising approach finally resulted in a steady number of referrals and inquiries about the project which eventually increased enrollment to the targeted levels.

Table TN-3 shows the number and proportion of cases who terminated during the application process and the reason for termination by quarter. The reasons for noncompletion of the application process varied somewhat from quarter to quarter but there was no clear or marked pattern to this variation. Overall, there were four major reasons that applicants did not enroll in the project. More than one-fourth of the applicants (27 percent) were found to have an ineligible medical diagnosis.

Table TN-3

Medicare Alzheimer's Project: Tennessee
Reason for Termination During the Application Process by Quarter
(January 1990 through June 1991)

REASON	1990								1991				TOTAL	
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Outside of Catchment Area			1	3	6	6	9	11	10	11	3	2	29	7
Ineligible Diagnosis	1	12	6	19	23	24	19	23	41	43	30	23	120	27
Did Not Have Medicare Part A and Part B	1	12	5	15	9	10	4	5			6	5	25	6
Unwilling to Consider Co-Payment											1	1	1	1
Refused to Sign Consent Form														
Refused to Accept Possibility of Control Group Assignment														
Found to be in Case Managed/ Duplicate Provider System														
Refused to Comply with Demonstration Requirements[a]	4	50	6	19	23	24	23	28	25	26	39	31	120	27
Institutionalized	1	12	12	38	21	22	15	19	9	9	18	14	76	17
Died	1	12	2	6	12	13	11	14	10	11	20	16	56	13
Physician Failed to Return Physician Form											10	8	10	2
Could Not Locate for Intake Interview														
Duplicate Applicant														
Not Interested[b]							3	10						
TOTAL[c]	8	98[c]	32	100	94	100	81	100	95	100	127	100	437	100

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] e.g., intake interview, follow-up interviews, case management.

[b] The two primary reasons reported under the "not interested" category were the client's family members could not all agree about participation or the potential client did not want to be in the project.

[c] Differences greater than or less than 100 are due to rounding.

Another 27 percent of the applicants did not enroll because they refused to comply with the demonstration requirements of an intake interview, follow-up interviews, and case management. Almost one-fifth of the applicants (17 percent) did not enroll because they were permanently institutionalized before the intake process was complete. Another 13 percent of the applicants died between the time the application form was requested and an intake interview was scheduled (normally a 2-week period if the physician referral forms were returned in a timely fashion). Other less frequent reasons for non-completion of the application process were: the applicant lived outside the catchment area (7 percent); the applicant did not have Medicare Part A or Part B (6 percent); the physician failed to return the physician referral form (2 percent) and the family was unwilling to consider the required co-pay (1 percent).

At the end of June 1991, there had been a total of 1,200 application requests for the demonstration and of these 437 were not completed. Thus, slightly more than one-third (36 percent) of those who began the application process did not eventually enroll.

Unlike most of the other demonstration sites, Tennessee did not have a higher than expected attrition rate during the caseload build-up phase of the project. The original research design estimated that 15 percent of the clients would attrite from the study primarily due to permanent institutionalization or death. At the end of the caseload build-up phase, 14 percent of study sample had attrited. Each case that attrited from the sample had to be replaced with a new client, which did increase the level of effort needed to conduct outreach and intake activities.

Case Management Services

Compliance with the Case Management Model

There were two different case management models being tested in the demonstration: Model A sites were to maintain a case manager-to-client ratio of 1:100; Model B sites were to maintain a case manager-to-client ratio of 1:30. Tennessee was a Model A site. To help ensure that each site maintained the appropriate case manager-to-client ratio during the caseload build-up phase of the demonstration, the sites were required to provide monthly reports to HCFA reporting the amount of time each case manager was spending on case management activities and the number of active cases assigned to each case manager. With this information it was possible to monitor the case manager-to-client ratio to determine if the project was complying with the Model A criteria of one case manager per 100 clients. The sites were allowed a 5 percent variance above or below the client-to-case manager ratio during the caseload build-up phase due to addition of clients, transitions in cases, addition of staff, etc. For the Model A sites, this variance could range from 95 and 105 active cases per case manager and not be out of compliance with the Model A criteria (e.g., new cases coming on; clients terminated due to death or institutionalization).

As the information in Table TN-4 shows, it took the Tennessee project nine months to reach the 1:100 case management model. Prior to October of 1990, the case manager-to-client ratio was consistently lower than the model guidelines, which permitted case managers to spend on average more time each month managing each client than specified for Model A sites. From October 1991 to March 1991, the case manager-to-client ratio decreased again, but then after May of 1991, each case manager had slightly more cases than "ideal" for the Model A sites.

Case Management Activities

Table TN-5 shows the proportion of time the case managers were spending in various case management related activities. The largest proportion of the case managers' time (41 percent) was being spent on service monitoring/follow-up after the initial care plan was developed. The initial assessment consumed 18 percent of the case managers' total time, followed by an additional 6 percent spent on the initial care plan. Record keeping and data entry also consumed a fair amount of the case managers' total time (13 percent). All other activities required less than 10 percent of the case managers' total time including outreach and intake, case conferences, caregiver education and training, public relations, administrative meetings, and local travel.

Demonstration Service Utilization Patterns

During the caseload build-up phase of the demonstration, the number of active clients rose slowly during the initial months of the project and then became more stable as awareness and acceptance of the demonstration project, increased overtime. As shown in Table TN-6, during the first two quarters of the project the number of active clients was relatively low. Then, enrollment began to increase and, by the second quarter of 1991, the project had on average 316 active treatment clients per month.

As with most of the other demonstration sites, of particular interest was the relatively high proportion of clients and/or caregivers who were electing to use only the case management service offered by the demonstration. For these clients and their caregivers there were no direct services such as in-home care or consumable care supplies being provided by the demonstration—only case management. During the early phases of the demonstration, there was a steady increase in the proportion of clients using only case management services beginning with 24 percent of the treatment group during the first quarter of 1990 and increasing to 41 percent of the treatment group during the second quarter of 1991.

The case managers have suggested the following factors impact service utilization patterns. Many caregivers and/or clients are reluctant to have people they do not know come into their homes and provide services such as a companion or home health aide. As the caregivers/clients become better acquainted with the case

Table TN-4

Medicare Alzheimer's Project: Tennessee
Compliance with the Model A Case Manager-to-Client Ratio of 1:100

Month	Case Manager to Client Ratio[a]
February 1990	1:46
March 1990	1:50
April 1990	1:76
May 1990	1:50
June 1990	1:53
July 1990	1:73
August 1990	1:69
September 1990	1:84
October 1990	1:100
November 1990	1:133
December 1990	1:76
January 1991	1:73
February 1991	1:88
March 1991	1:84
April 1991	1:100
May 1991	1:106
June 1991	1:123

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] The average case manager-to-client ratio was derived by dividing the total hours each case manager spends on case management activities each month by the number of clients assigned to the case managers that month. The average hours spent per case-managed client were then converted to a ratio by dividing the number of hours per client by the total hours worked in an average month (i.e., 168 hours). In the Model A projects, with a 1:100 case manager-to-client ratio, each client should receive approximately 1.5 hours of case management per month.

• The sites were allowed a 5% variance above or below the case manager-to-client ratio during the caseload build-up phase due to additions of clients, transitions of cases, additions of staff, etc. For the Model A sites, this variance could range from 95 to 105 clients per case manager and not be out of compliance with the Model A criteria.

Table TN-5

Medicare Alzheimer's Disease Demonstration: Tennessee Case Management Activities

Activity	Percent Time Spent in Each Activity[a]
Outreach and Intake	7
Initial Assessment	18
Initial Care Planning/Service Arrangement and Costing of Care Plan	6
Case Conferences	1
Service Monitoring/Follow-up	41
Caregiver Education and Training	2
Public Relations	<1
Administrative/Supervisory Meetings, Reports	3
Record Keeping/Data Entry	13
Local Travel	9
Other	<1
TOTAL	**100**

[a] Each case manager completed a time study allocating the total number of hours typically spent during a week in various activities. The time study was completed in the summer of 1990, during the case load build-up phase of the demonstration.

managers and the program, it was anticipated that families would be more willing to accept services over time. Inability to pay the co-pay was also cited as a reason for caregivers/clients not using services, although the project made every effort to have the co-pay waived by the provider agency when it represented a hardship. Finally, the location of the one day care program was such that it was not feasible for many clients to use the service. With respect to day care, many families also felt that the cost ($32 per day) was too high, and given the cap under Model A, would elect to use less costly services such as in home chore services. The case managers predicted that over time utilization of demonstration services would gradually increase.

Table TN-6

Medicare Alzheimer's Project: Tennessee
Services Use Patterns by Quarter
(March 1990 through June 1991)

Service Use	1990								1991			
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Average Number Active Treatment Clients per Month	58	100	93	100	145	100	206	100	254	100	316	100
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	44	76	77	83	95	65	131	64	168	66	171	54
Average Number Treatment Clients Receiving Case Management Only	14	24	16	17	40	28	68	33	72	28	129	41
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	NA[a]		NA[a]		10	7	7	3	14	6	16	5

[a] NA = Data not available.

MODEL B SITES

MIAMI, FLORIDA - MIAMI JEWISH HOME AND HOSPITAL FOR THE AGED

History and Sponsorship

The MJHHA, the largest long term care facility in the Southeast with 700 residents (600 on the campus site, 100 elsewhere), sponsors the Medicare Alzheimer's Disease Demonstration project in the Miami, Florida metropolitan area. MJHHA is a comprehensive geriatric care facility. It provides community-based social and health services as well as long-term institutional care, including a special Alzheimer's unit and case management, adult day care (including Alzheimer's day care), mental health and home health care services. MJHHA has a $15 million per year budget for non-institutional services. Institutional services have a $25 million per year annual budget.

In the 1970's, MJHHA began developing community-based services, with day care and community mental health services. In the early 1980's, MJHHA was awarded a channeling case management demonstration contract and later developed Medicare home health. During this same period, MJHHA also developed a research institute to promote independence in the elderly population of Miami. In 1987, MJHHA began a therapeutic inpatient program for Alzheimer's victims and a community-based Alzheimer's Day Care Center. Today, MJHHA consults with other facilities (e.g., nursing homes, adult congregate living facilities) in the development of their specialized programs. The channeling program has continued at MJHHA under funding from the State Medicaid program. It continues to operate as it did under the Medicare demonstration except that MJHHA now uses state criteria for nursing home eligibility. MJHHA currently serves over 5,000 clients annually in all of its programs. This includes 500 long term care beds, plus 4,500 clients in its array of community-based programs.

In addition to MJHHA's institutional and community care service capacity, it has ongoing research and education capability in the Stein Gerontological Institute (SGI). Research conducted through the SGI includes environmental assessment, adaptive technology research, and robotics engineering. SGI also has full-time training staff to develop curricula and train all levels of personnel on the technological developments made by the research unit as well as on health care and gerontological issues. MJHHA operates two adult day care programs serving 80 clients per day (300/year); ambulatory health services serving 1,000 unduplicated clients per year; an Alzheimer's adult day care program serving 25 clients a day (100/year); a case management program serving over 750 active cases; a community mental health center serving 2,500 unduplicated clients per year; a geriatric residential treatment center with 70 residential beds; a congregate living facility with 124 residents; short term emergency management system serving 325 clients a year; the SGI, the Mt. Sinai/MJHHA home health agency conducting 10,886 visits per year; and the MJHHA nursing home with 397 long term care beds, 40 rehabilitation beds, a 32 bed specialty hospital, and a 29 bed Alzheimer's unit.

While MJHHA has a long-standing history of service delivery to the elderly in Miami and a well-developed system of cooperation and coordination among other service providers in the area, MJHHA staff decided to develop their proposal independently of other major health care providers as well as the local state university. This was done, in part, because a competing consortium of providers (e.g., Mt. Sinai Hospital and the University of Miami, several nursing homes and local community service providers) were also competing for the Alzheimer's demonstration.

The MAP, as it is known in the community, began as an extension of the work already being done within MJHHA. A number of MJHHA departments were utilized during the development and implementation of the MAP project, including the education department, which was a resource to MAP in organizing and training MAP staff, home health aides, as well as MAP caregivers in Alzheimer's related issues. Staff physicians and psychologists helped in the development of the MAP client assessment instrument. The MJHHA management information systems department helped select hardware and software for the MAP MIS system and then programmed it. The fiscal department handles financial cost tracking and cost reporting systems for MAP, and the public affairs department worked with MAP in developing news releases, brochures, and other publicity for the program.

Having an experienced project director already on the MJHHA staff allowed work to begin on the project before actual funding was distributed. Some of the early implementation activities conducted by the in-house personnel included adapting some of MJHHA's existing program policies and procedures to the MAP project (e.g., the existing channeling case management program), interviewing and hiring staff, and developing intraorganizational linkages (e.g., with the fiscal and MIS departments) needed when project implementation was begun.

Intraorganizational Structure

During 1987, the MJHHA served over 1,300 clients with diagnoses of Alzheimer's and related disorders. This included the Community Mental Health Center, the channeling case management program, the long-term care facility, and the assessment unit. MJHHA has made the Alzheimer's and related dementia services a priority. MAP has enabled MJHHA to seek clients from more sources and to increase its catchment area to include more of Broward County.

The MAP serves two counties in the greater Miami area: Dade County and parts of southern Broward County. A great deal of time has been spent in developing referral contacts and negotiating service delivery contracts with providers in Broward County, since MJHHA had not served this area before. While the service delivery environment is similar in the two counties, the demographics are not. Dade county is 42 percent Hispanic and 20 percent Black whereas Broward county is mostly White. The MAP catchment area (Dade County and South Broward County) contains approximately 400,000 elderly.

The MAP demonstration is located within the MJHHA Community Services Division. The Project Director for MAP is also responsible for all care management and home delivered services for MJHHA, but these units and MAP each have their own staff. The Project Director and the Associate Executive Director of Community Services meet on a regular basis to administer the program.

The MAP program was set up as a separate unit, separate even from the existing MJHHA case management program. This was done for a number of reasons: one, space. The MAP program was estimated to need approximately 25 staff and there was no room for that many new staff in the established case management division of MJHHA. A second reason for the separation was that more efficient financial tracking could be provided to the MAP program if it were separate from the existing case management program. A third reason was that the MAP caseloads would be somewhat smaller than those of the existing case management program and the needs of the clients would be difference (e.g., medically-oriented needs). Fourth, the programs were kept separate because the clients in the existing program were primarily non-dementia clients (e.g., only a quarter to one-third of the caseload was dementia) so that a program that focused on just dementia patients needed to be segregated in terms of location, staffing, and organizational relations. Finally, stipulations in the original HCFA RFP required separate quarters for MAP intake workers and case management staff to avoid treatment/control group contamination.

Overall, the MAP program is well-integrated into the organizational hierarchy of the Miami Jewish Home. Generally, the project works directly with other organizational units on a particular task but the MAP project also subcontracts with divisions in the organization, primarily the day care and home care programs.

The two MJHHA case management staffs often participate in joint in-service training, and the fiscal billing and service authorization forms and procedures between the two units are almost identical. Conversely, the assessments that must be conducted on the MAP clients are very different from those of the existing case management program, especially in the identification of caregiver burden and availability and the amount of financial information required for MAP clients. The MAP assessment instrument also has a "scored assessment procedure" from which the care plan is developed. The new procedures developed for the MAP program are being tested by MJHHA through the demonstration and, if successful, the existing case management program will adopt these procedures.

Issues that arose during the implementation of the MAP demonstration were: the massive amounts of personal energy and organizational resources needed to plan for and implement the outreach component of the program; the effort required to put together the MIS system for the MAP program; the necessity of partitioning Broward County (i.e., serving only the southern portion of the county) has been a small public relations problem for MJHHA (although trying to monitor service to clients in the northern part of the county would have been very cumbersome due to the long distance between Miami and the northern part of Broward). Therefore, it was decided that, because there would be more than enough potential clients in Dade and South Broward County and because MJHHA had no experience with the service providers in North Broward County, it was not necessary.

Figure FL-1 is a chart identifying overall responsibility for performance of key project functions.

Program Staffing

Table FL-1 shows the demonstration program's staffing pattern during the period when the program was building toward its original enrollment goal of 360 active treatment group clients at the end of April 1991. The total number of demonstration full and part-time staff members was 24 for a total of 23.8 FTE staffing positions. There were 3.95 full time equivalent FTE administrative/finance staff including the project director and the case management supervisor; 1.6 FTE outreach and intake personnel; 13.3 FTE case management staff; a .75 FTE staff position to conduct education and training activities; 2.4 FTE support staff; and 1.8 FTE to manage the program's management information system.

Staff Experience

The majority of key staff involved in the demonstration, including the project director, assistant project director, the case management supervisors, and

Figure FL-1

Medicare Alzheimer's Project: Florida
Responsibilities for Primary Project Functions

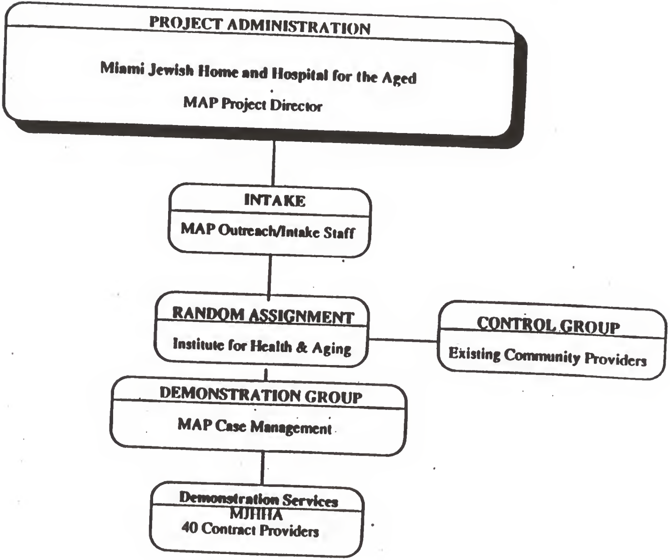

PROJECT ADMINISTRATION
Miami Jewish Home and Hospital for the Aged
MAP Project Director
INTAKE
MAP Outreach/Intake Staff
RANDOM ASSIGNMENT
Institute for Health & Aging
CONTROL GROUP
Existing Community Providers
DEMONSTRATION GROUP
MAP Case Management
Demonstration Services
MJHHA
40 Contract Providers

Table FL-1

Medicare Alzheimer's Project: Florida Demonstration Staffing Patterns

Functional Activities	(Full-Time Equivalent Staff) (April 1991)
Administrative/Finance	3.95
Outreach/Intake	1.60
Case Management	13.30
Education/Training	.75
Research Assistant	0
Support Staff	2.4
Other (MIS)	1.8
TOTAL STAFF	23.8

many of the case managers, outreach and intake workers have had extensive experience in community-based long-term care and working with the elderly. In addition, many of the staff, including the director, have had experience in behavioral science research. The director and one case manager were with the organization prior to the demonstration award with the rest of the staff being hired specifically to work for the project. The director and assistant project director, as well as some of the case management staff, all have graduate degrees in a human service or administrative field (e.g., nursing, social work, business administration, health care management). Some staff did have prior experience working with Alzheimer's patients and their families. All staff received a number of training and information sessions on Alzheimer's prior to the implementation of the program. The MJHHA education and training staff, as well as the demonstration's physician and psychologist consultants, worked closely with all the demonstration staff to impart their specialized knowledge about the Alzheimer's population and their needs through formal training sessions and in day-to-day informal information transfer sessions.

There were few special problems in finding qualified staff for the program. However, there was a general shortage of nurses in the Miami area and the salary differential between nurses and social workers had to be addressed by the demonstration. There were more bilingual applicants to the program than expected and this necessitated recruiting more bilingual staff, including bilingual intake workers. This became a priority when the second set of case managers was hired.

Service Environment

The Community Long Term Care Service System

Overall, the greater Miami area is considered by service providers to be a resource rich area, especially if the individual has the money to pay for services. There are numerous health care providers, hospitals, nursing homes, and home care providers. If the individual is on Medicaid, the services are also there, although somewhat more limited in terms of accessibility, availability, and quality.

Table FL-2 summarizes the Dade/South Broward County catchment area by scoring community-based services according to their availability, accessibility, and quality of care. The scores were obtained from knowledgeable spokespersons in the Miami service area and are an average based on scores for those with resources and those on Medicaid or without services. The resources in Dade County were considered to range from high to medium in

Table FL-2

Medicare Alzheimer's Project: Florida
Community Spokesperson's Ratings on the Availability, Accessibility, and Quality of the Long Term Care Service System

Service Type	Maximum Points[a]	Catchment Area Scores[b]	
		Dade County	Broward County
Integrative Services			
Case Management		6	5
Geriatric Assessment		5	5
Information and Referral		6	5
Subtotal Points	27	17	15
Home Health Care			
Skilled Nursing		7	7
Therapies		7	7
Social Services		7	7
Home Health Aides		7	7
Subtotal Points	36	28	28
Home Support Services			
Homemaker/Chore Services		6	6
Personal Care Services		6	6
Meals (home & community)		6	6
Adult Protective Services		4	3
Mental Health Counseling		6	6
Transportation		5	6
Subtotal Points	54	33	33
Special Purpose Services			
Hospice Care		6	7
Day Health Care		7	6
Social Day Care		7	7
Respite Care		6	6
Training for Informal Caregivers		4	5
Support Services for Informal Caregivers		4	5
Subtotal Points	54	34	36
Living Arrangements			
Senior Citizens Housing		4	5.5
Congregate Housing		3	5
Board and Care/Residential Care		6	6
Foster Care		3	5
Intermediate Care Facility		5	6
Skilled Nursing Facility		6	7
Subtotal Points	54	27	34.5
TOTAL POINTS[c]	225	139	146.5

[a] Each service type was ranked on a scale of 0 to 3 on the dimensions of availability (0=None, 1=Low, 2=Medium, 3=High), accessibility (0=None, 1=Low, 2=Medium, 3=High), and quality (0=None, 1=Low, 2=Medium, 3=High). The service score for each service type could range from 0 to 9. The maximum service points within service subgroups and the total possible points across all long-term care services within a catchment area are shown in column 2.

[b] In catchment areas serving more than one county, the ratings for each county were totaled and then an average score was calculated.

[c] Score range = 0 to 255; 0-75 = Poor Long Term Care Service System; 76-150 - Fair Long Term Care System; 151-255 - Well Developed Long Term Care System.

availability, accessibility, and quality for those with the resources to pay for them and ranged from medium to low for those who are low-income. The scores were more similar for the providers in South Broward County and ranged from high to medium. The highest scores were obtained for home health care and home support services in Dade County and for home support services, special purpose services (such as hospice and day health), and home health care in Broward County. Dade County scored higher in integrative services (e.g., case management services, geriatric assessment) while Broward County scored higher on living arrangement services (senior citizens housing).

There are services in the area targeted specifically to Alzheimer's patients. These include three diagnostic and treatment centers, adult day health, respite care, support groups, SNFs with special Alzheimer's units, and adult congregate living facilities (ACLFs) that specialize in Alzheimer's disease. There is no special SNF rate for these cases. ACLFs generally get a higher private pay rate for their units. Overall, there is huge variability in quality, accessibility, and cost in the Miami catchment area. The MAP program excluded Alzheimer's cases who were living in the Alzheimer's Specialized Care Facilities since their needs were largely being met by the facility.

There are also a number of "case management" programs similar to the MAP program in the Miami area including the Community Care for the Elderly (CCE), Hospice, Elder Care programs, MJHHA's Channeling Program and Metro-Dade Elderly Services Care Planning Unit. The CCE program has case loads of 100-130 per case manager and provided seven core services: adult day care, homemaker, personal care, home health aides, transportation, meals, and respite care. The program is funded by the Older Americans Act, state general revenues and Medicaid waiver funds. The program is administered by one lead agency in Broward and one in Dade County. Each lead agency subcontracts for their services to other providers in the area. Service eligibility is based on Older Americans Act guidelines of age 60 or older and the Older Americans Act disability criteria. The MAP program considered this program duplicative case management for purposes of randomization.

The Elder Care program is funded under a Medicaid waiver at Mt. Sinai Hospital and is structured like a Social Health Maintenance Organization (S/HMO) and includes community services and medical care. Patients in the program had to lock-in to their "managed" care system. Participants in the channeling program and hospice were also excluded from enrollment due to the intensity of the intervention offered by these programs. Finally, the Metro-Dade Elderly Services unit also offers case management, homemaker, and adult day care services. Anyone qualifies who meets Medicaid eligibility or is medically indigent. The MAP program also considered this program duplicative of case management services.

There are three Alzheimer's diagnostic centers in the Miami area and a group practice of neurologists that do a lot of drug studies. They run newspaper ads seeking volunteers. These programs, in some sense, were competing with the MAP project for participants.

The usual entry points for Alzheimer's patients into the community care system are all of the providers listed above as well as the two Alzheimer's Diagnosis Centers, the Alzheimer's Association Elder Help Lines sponsored by the Area Agency on Agency, and all the discharge planning units in the area's hospitals. The reported barriers to the system include client and family level issues such as denial of the disease and the stigma attached to it. Language and cultural barriers in the community may result in a "segregation" of providers, i.e., they serve particular ethnic groups. Additionally, individuals from minority groups often do not go beyond these known service providers when the service needed is not available. There is also the problem that clients often prefer to be among ethnically homogeneous groups. Miami is racially diverse with divisions within specific minority groups (e.g., about 15 percent of the Hispanics are non-Cuban; that is, they are from Central or South America). There is also white "segregation" in that there are Jewish and non-Jewish groups. Finally, there is some inequity in its geographic distribution of services. Everything is not equally available throughout the catchment area.

Demonstration Service Providers

Case management is an integral component of both the inpatient and community-based MJHHA programs. MJHHA operates two day care centers plus a special Alzheimer's Day Care program. MJHHA contracts with 40 different providers, often for multiple services, in Dade and Broward Counties to provide the following services:

- case management (exclusively MJHHA/MAP staff)
- skilled nursing (4 contracts-including 1 with MJHHA)
- therapy (physical/speech/occupational) (4 contracts including 1 with MJHHA)
- home health aide (3 contracts-including 1 with MJHHA)
- homemaker/personal care (7 contracts-including 1 with MJHHA)
- housekeeping (2 contracts)
- adapt/assist equipment-physical (4 contracts)
- adapt/assist equipment - cognitive (5 contracts)
- medical supplies (5 contracts-including 1 with MJHHA)
- durable medical equipment (2 contracts)
- consumable care goods (3 contracts)
- mental health (psychosocial evaluation) (2 contracts)
- chore services (general/repairs and maintenance) (3 contracts)

- transportation (1 contract)
- home delivered meals (5 contracts)
- family counseling (2 contracts)
- adult day care (14 contracts-including 3 with MJHHA)
- companion for caregiver education/training (8 contracts-including 2 with MJHHA)
- medical assessment (1 contract with MJHHA).

The project director for MAP is responsible for negotiating the contracts needed within the catchment areas. Generally, the demonstration project is matching each service provider's prevailing rate. However, several of the providers were willing to negotiate a slightly reduced rate with the MAP project. MAP elected to deal with providers with whom they had had previous experience in Dade County but had to find providers in Broward. While the rates were individually negotiated with the providers, the competition among the providers was so intense that they did not find it necessary to go out for bids.

There were some minor service delivery problems encountered by MAP during the program implementation phase of the project. The MAP program found that there were some access problems in South Broward County for day care due to the lack of an Alzheimer's specific program. A second problem concerned home health aides. The home health aide employee population in Dade county is primarily composed of minorities including Hispanics, Haitians and Jamaicans. When the program did their initial training, many of the aides did not comprehend English, so simultaneous translations of the training were provided in Spanish. While the biggest problem the program was having with the aides is a language barrier, they are also having problems with aides not showing up for work or not showing up on time. There are also some racial and cultural problems from the point of view of the clients, who are predominantly white. Additionally, finding aides at special hours, such as nights or weekends, is very difficult.

Outreach and Enrollment

Program Census

The Miami MAP catchment area includes all of Dade County (Miami and surrounding areas) and South Broward County (from Fort Lauderdale and south to the Dade County line). This area encompasses nearly two million people, of whom about 580,000 are over the age of 65. Some 335,000 elderly reside in Dade County; the rest live in Broward County. Currently there are more than 80,000 Medicare recipients in South Broward and the number is growing rapidly. Under the assumption that 4 percent of the elderly would be cognitively impaired as a result of Alzheimer's or related dementias, it was estimated, that in the Dade-Broward catchment area, at least 23,200 of those over age 65 may be suffering from some form of dementia. Based on the above estimates, the Miami MAP initial project census was 720 (360 treatment group clients and 360 control group clients). On April 30, 1991, MAP had exceeded its original project census and had enrolled 738 clients in the program (371 treatment and 367 control). MAP subsequently enrolled a total of 432 treatment participants.

Difficulties Encountered Reaching Enrollment Goals

While the Miami MAP demonstration was able to meet its projected client census, there were periods of time when they were behind their projected census. Unanticipated difficulties in locating and recruiting eligible clients, half of whom were randomized into the control group, proved to be a challenge during the case load buildup phase.

Table FL-3 shows the number and proportion of cases who terminated during the application process and the reason for termination by quarter through June 1991. At the end of June 1991, there were 1,060 application requests for the demonstration; of these applications, 134 were not completed. The reasons for noncompletion of the application process fluctuated somewhat from quarter to quarter and there was no clear pattern to the fluctuations. The most frequent reason for noncompletion of the application process was that applicants had been institutionalized prior to their being enrolled in the demonstration (24 percent). The second most frequent reason fot termination was that the client and/or caregiver refused to comply with the Demonstration requirements (e.g., refused to be randomized, refused the 20 percent co-payment requirement, refused case management assessment). Overall, 19 percent of the non-completed applicants were terminated for this reason. The third most frequent reason for application termination was that the client lived outside of the program's catchment area (14 percent).

The next most frequent reason for termination occurred because the applicant did not have Medicare Part A and Part B coverage (10 percent). In most cases, lack of Medicare Part A coverage disqualified the applicant. Additional reasons for not completing applications were: the applicant died prior to completing the process or was found to be in a duplicative case management program (9 percent); could not be located by MAP staff to complete an intake interview (5 percent); or had an ineligible diagnosis (4 percent). Three applicants (2 percent) did not complete applications because they were not interested in the project. Throughout the project, obtaining completed Physician's Referral Forms was a problem, particularly during peak intake when 100 or more Physician's Referral Forms were outstanding at any given time.

The demonstration encountered more difficulty in reaching its enrollment target than expected. Major efforts were undertaken to get the word out on

Table FL-3

Medicare Alzheimer's Project: Florida
Reason for Termination During the Application Process by Quarter
(January 1990 through June 1991)

REASON	1990								1991				TOTAL	
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Outside of Catchment Area	1	14	4	22			4	12	6	24	2	7	17	14
Ineligible Diagnosis	1	14			1	4	3	9	1	4			6	4
Did Not Have Medicare Part A and Part B			4	22	4	18	5	15	1	4			14	10
Unwilling to Consider Co-Payment							1	3					1	1
Refused to Sign Consent Form														
Refused to Accept Possibility of Control Group Assignment							1	3					1	1
Found to be in Case Managed/ Duplicate Provider System			2	11	3	13	4	12	1	4	2	7	12	9
Refused to Comply with Demonstration Requirements[a]	3	43	1	6	6	26	5	15	6	24	5	19	26	19
Institutionalized	2	29	6	33	5	22	7	21	6	24	6	21	32	24
Died			1	6	1	4	2	6	1	4	7	25	12	9
Physician Failed to Return Physician Form									2	8			2	1
Could Not Locate for Intake Interview					1	4					6	21	7	5
Duplicate Applicant							1	35					1	1
Not Interested[b]					2	9			1	4			3	2
TOTAL	7	100	18	100	23	100	33	99	25	100	28	100	134	100

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] e.g., intake interview, follow-up interviews, case management.

[b] The two primary reasons reported under the "not interested" category were the client's family members could not all agree about participation or the potential client did not want to be in the project.

the program including a heavy reliance on newspaper advertising and working very closely with traditional referral sources to get them to change their referral patterns and refer to the new program (e.g., hospital discharge planners). Demonstration staff found some resistance in the community to referring clients to a "demonstration" that had the potential for randomization into a control group, and, perhaps, a bit of turf protection. They also found that the local HMO's were reluctant to refer clients thinking that Medicare would not pay for MJHHA services and the HMO would be billed or that MJHHA would "commandeer" the client. The staff felt that the oversupply of providers in the Miami area worked against their outreach efforts to some degree since everyone is cautious about losing cases to another program.

Case Management Services

Compliance with the Case Management Model

To help ensure that each site maintained the appropriate case manager-to-client ratio during the caseload build-up phase of the demonstration, the sites were required to provide monthly reports on the amount of time each case manager was spending on case management-related activities and the number of active cases for each case manager. With this information, it was possible to monitor the case manager-to-client ratio to determine if the project was complying with the Model B criteria of one case manager to 30 clients. Sites were allowed a 5 percent variance above or below the case manager-to-client ratio due to addition of clients, transitions in cases, additional staff, etc. For the Model B sites, the variance could range from 28 to 32 clients per case manager during the caseload build-up phase and still not be out of compliance with Model B criteria.

To be in compliance with the 1:30 case management model, in the Model B sites, the case managers should be spending, on average, between 5 and 5 1/2 hours per month per active client. The data in Table FL-4 show that for 4 of the 17 months of the caseload build-up phase, the Miami demonstration was in compliance with Model B case manager-to-client ratio. During the rest of the caseload build-up phase, the Miami site case manager-to-client ratio was above the 1:30 model. This meant that for most of the caseload build-up phase, Miami case managers were spending less than the required 5 to 5 1/2 hours in case management activities with clients.

Case Management Activities

Case managers at the Miami MAP demonstration were spending their time in a variety of activities. Table FL-5 presents data showing the average percent of time all case managers at the Miami site were spending in a

Table FL-4

Medicare Alzheimer's Project: Florida (Miami)
Compliance with the Model B Case Manager-to-Client Ratio of 1:30[*]

Month	Case Manager-to-Client Ratio[a]
February 1990	1:23
March 1990	1:30
April 1990	1:33
May 1990	1:36
June 1990	1:46
July 1990	1:34
August 1990	1:33
September 1990	1:37
October 1990	1:35
November 1990	1:27
December 1990	1:39
January 1991	1:48
February 1991	1:47
March 1991	1:49
April 1991	1:43
May 1991	1:38
June 1991	1:40

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] The average case manager-to-client ratio was derived by dividing the total hours each case manager spends on case management activities each month by the number of clients assigned to the case managers that month. The average hours spent per case-managed client were then converted to a ratio by dividing the number of hours per client by the total hours worked in an average month (i.e., 168 hours). In the Model B projects, with a 1:30 case manager-to-client ratio, each client should receive approximately 5.3 hours of case management per month.

[*] The sites were allowed a 5% variance above or below the client-to-case manager ratio during the caseload build-up phase due to additions of clients, transitions of cases, additions of staff, etc. For the Model B sites, this variance could range from 28 to 32 clients per case manager and not be out of compliance with the Model B criteria.

Table FL-5

Medicare Alzheimer's Disease Demonstration: Florida Case Management Activities

Activity	Percent Time Spent in Each Activity[a]
Outreach and Intake	7
Initial Assessment	11
Initial Care Planning/Service Arrangement and Costing of Care Plan	11
Case Conferences	6
Service Monitoring/Follow-up	23
Caregiver Education and Training	7
Public Relations	0
Administrative/Supervisory Meetings, Reports	7
Record Keeping/Data Entry	17
Local Travel	11
Other	
TOTAL	100

[a] Each case manager completed a time study allocating the total number of hours typically spent during a week in various activities. The time study was completed in the Summer of 1990, during the case load build-up phase of the demonstration.

number of pertinent activities. As can be seen in the table, almost a quarter of the case managers' time was spent in service monitoring and follow-up activities (23 percent). Other activities accounting for case managers time included record keeping/data entry activities (17 percent), initial client assessment, initial care planning/service arrangement, and travel to and from client's homes (each 11 percent of time). Finally, case managers were spending about 7 percent of their time in each of the following activities: outreach and intake activities, in caregiver training and education activities, and in administrative/ supervisory meetings. Case managers also spent about 6 percent of their time in case conferences meetings with other case managers/supervisors/and/or providers.

Demonstration Service Utilization Patterns

During the caseload build-up phase of the demonstration, the number of active clients rose steadily at the Miami site. As shown in Table FL-6, by the fourth quarter of 1990, the Miami MAP program averaged 296 clients per month and by the second quarter of 1991, the Miami MAP program averaged 362 active clients per month. Of particular interest was the relatively high proportion of client/caregivers who were electing to use only the case management services offered by the Demonstration. The percentage of client/caregivers that received case management only ranged from a low of 9 percent in the first quarter of 1991 to a high of 21 percent in the fourth quarter of 1990. It is not clear why the proportion of client/caregivers using only case management services was relatively high during the third and fourth quarters of 1990 or why the percentage decreased during the first two quarters of 1991.

The case managers have suggested that some of the factors affecting the decision to accept services include: newly diagnosed clients do not yet require additional services beyond case management; some families are reluctant to accept services, either due to the stigma attached to Alzheimer's, reluctance to allow strangers into their homes, or, sometimes, because the client is unaware of their diagnosis and families are unwilling to have services that might alert the client to their disease. A major factor has been the reluctance of clients to co-pay for services (either unwilling or unable to do so). Furthermore, there often is a discrepancy between what the case manager and program have to offer the families and what the client/caregiver wants from the program.

Table FL-6

Medicare Alzheimer's Project: Florida
Services Use Patterns by Quarter
(March 1990 through June 1991)

Service Use	1990								1991			
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Average Number Active Treatment Clients per Month	64	100	104	100	229	100	296	100	330	100	362	100
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	52	81	93	89	183	80	235	79	296	90	322	89
Average Number Treatment Clients Receiving Case Management Only	9	14	11	11	41	18	61	21	30	9	37	10
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	3	5			5	2			4	1	3	1

ST. PAUL, MINNESOTA - AMHERST H. WILDER FOUNDATION

History and Sponsorship

The Minnesota Alzheimer's Consortium, which sponsors the MAD, is comprised of four organizations: the Amherst H. Wilder Foundation; the Metro-Minneapolis/St. Paul Chapter of the Alzheimer's Association; the Ebenezer Society; and the Miller-Dwan Medical Center.

The Amherst H. Wilder Foundation, the lead agency in the consortium, is a large foundation with over 80 years of experience promoting the social welfare of persons residing in the greater St. Paul metropolitan area. While the Foundation has a large private endowment for program development and funding of some special programs, the Foundation is also a non-profit service provider to more than 23,000 individuals. The Elderly Division, the largest component of the foundation, offers a continuum of services including nursing homes, senior housing, and community-based long term care programs.

The Metro-Minneapolis/St. Paul Chapter of the Alzheimer's Association is a founding member and one of the largest chapters in the National Alzheimer's Association with over 1,839 active members. The chapter has generated a number of Alzheimer's related initiatives. It sponsors 45 family-oriented support groups throughout the State and conducts numerous seminars and workshops in the care of persons with dementing illnesses.

Ebenezer Society is a major provider of senior services in the greater Minneapolis area. Founded in 1917, Ebenezer has broad experience in service provision for the impaired elderly including four nursing home facilities, seven senior housing facilities, and an array of community-based long-term care services. Ebenezer also received an National Institute for Mental Health grant to publish a 13-part series on human development and aging, with special attention given to the effects of dementias.

Miller-Dwan Medical Center, through its subsidiary Quetico LifeCare Corporation represents the rural component of the Minnesota Consortium. As the leading regional specialty hospital in the Duluth area, Miller-Dwan offers one of the few rural-based Alzheimer's programs in the nation. Its Alzheimer's Residential Care program has been cited as a national model in the care of Alzheimer's victims who are unable to live at home but need 24-hour supervision.

The Minnesota Alzheimer's Consortium, the partnership developed to sponsor the Medicare Alzheimer's Demonstration, was the result of a number of Minnesotans involved at the national, state, and local level in health care related issues who had for a number of years been looking for a mechanism to develop community-based services for individuals and the families of individuals with Alzheimer's disease.

At the national level, members of the local Alzheimer's Association, served on the board of the National. At the state level, the governor had an Alzheimer's task force which prepared a report on the need for services, but had no money to implement the recommended service system. At the local level, in the St. Paul area an innovative organization, the Alzheimer's Care Network, had been formed as a prototype for developing a continuum of care for both the client and the caregiver. Also at the local level key individuals at Wilder Foundation, Alt Care Corporation (a joint venture between General Mills and Wilder Foundation designed to foster the development of health care innovations), and the local chapter of the Alzheimer's Association had been having a number of formal and informal discussions about how to develop a better system of care for Alzheimer's victims and their families. They had followed the legislation enabling the demonstration and were waiting for HCFA to issue the RFP.

When the demonstration RFP was issued, and after reviewing the basic requirements, it was decided that it would be difficult to obtain the number of demonstration clients needed in the time period specified and to run an efficient system if there was only one site in the St..Paul area. At that point the key actors from the St. Paul area organizations began looking for potential partners. Ebenezer Society was approached because of its service provider reputation in the greater Minneapolis area and it had earlier contacted the Alzheimer's Care Network about replicating that program in Minneapolis. The RFP also appeared to be requesting a rural constituency and both Wilder Foundation and Ebenezer Society serve metropolitan areas. At that stage, the director of the Alzheimer's Residential Care Homes in Duluth, who is affiliated with the Miller-Dwan Medical Center which services the rural greater Duluth area, was approached as a potential partner in the demonstration. After several meetings it was agreed that a consortium would be formed with Wilder Foundation playing the lead role, both in the development of the RFP and in the implementation and management of the demonstration project.

Intraorganizational Structure

The program operates out of four different physical locations but serves only three distinct catchment areas. The Wilder Foundation houses the principal administrative and fiscal staff, including the demonstration's project director, the Wilder site director, the fiscal manager, and the case management supervisory staff as well as the site's own project director and the case management staff for those clients being served in the greater St. Paul catchment area (including Ramsey County, Dakota County, Washington County, and Anoka County). Ebenezer Society houses its site director and case management staff for clients residing in the greater Minneapolis catchment area (Hennipen County). Miller-Dwan houses its site director and case management staff for clients served in the rural area surrounding and north of Duluth (St. Louis County). All of the demonstration's direct services (e.g., home health aides, homemakers) are provided directly by or under contract with Wilder, Ebenezer, and Miller-Dwan. Finally, the Metro-Minneapolis/St. Paul

Chapter of the Alzheimer's Association houses the program staff responsible for managing and conducting the demonstration outreach and intake activities (with the exception of one Intake Worker located in Duluth, but supervised from the central office). The Alzheimer's Association is also responsible for training functions and the grievance procedure. Figure MN-1 is a chart identifying overall responsibility for performance of key project functions.

Program Staffing

Table MN-1 shows the demonstration program's staffing patterns when the program reached its enrollment goal of 420 active clients at the end of April 1991. As noted earlier, overall project management was conducted by staff stationed at Wilder Foundation. These staff (the MAP project director, the case management coordinator, and the financial manager) are included in the administrative/finance category for Wilder Foundation staffing. Each of the three sites that provided case management and direct services also have a part-time project director, a case management supervisor, case managers, and a small support staff. The one major difference between sites was the number of case managers–which was determined by the number of clients enrolled at each site. Ebenezer Society in Minneapolis, had the largest client caseload with 7.6 FTE case managers; Wilder Foundation in St. Paul had the next largest caseload with 5.24 FTE case managers; and Miller-Dwan Medical Center in Duluth had the smallest caseload with 2.3 FTE case managers.

The Alzheimer's Association was responsible for all outreach and intake activities and for education and training. These responsibilities are reflected in the staffing pattern for the project. The director of the Association spent .25 percent of his time on the demonstration project, and there were 2.42 FTE outreach and intake workers. The outreach and intake supervisor spent approximately .28 FTE of her time conducting education and training programs. There was one FTE support staff person who assisted primarily with outreach and intake.

Staff Experience

Almost all of the key staff involved in the demonstration, including the directors, the supervisors, the case managers, and the outreach and intake workers, have extensive experience with other community-based service programs for the elderly. Many have been long-term employees of the Wilder Foundation, Ebenezer Society or Miller-Dwan Medical Centers. Many of the staff also had some experience with people with dementia. The consortium's resource for expertise with issues specific to Alzheimer's and other related dementias was the Metro-Minneapolis/St. Paul Chapter of the Alzheimer's Association and the supervisory staff which they subsequently hired to head the outreach and intake and the education and training components of the demonstration. These individuals worked closely with other demonstration staff imparting their specialized knowledge about the study population and its needs through extensive formal training sessions, as well as the day-to-day informal transfer of information.

Figure MN-1

Medicare Alzheimer's Project: Minnesota Responsibilities for Primary Project Functions

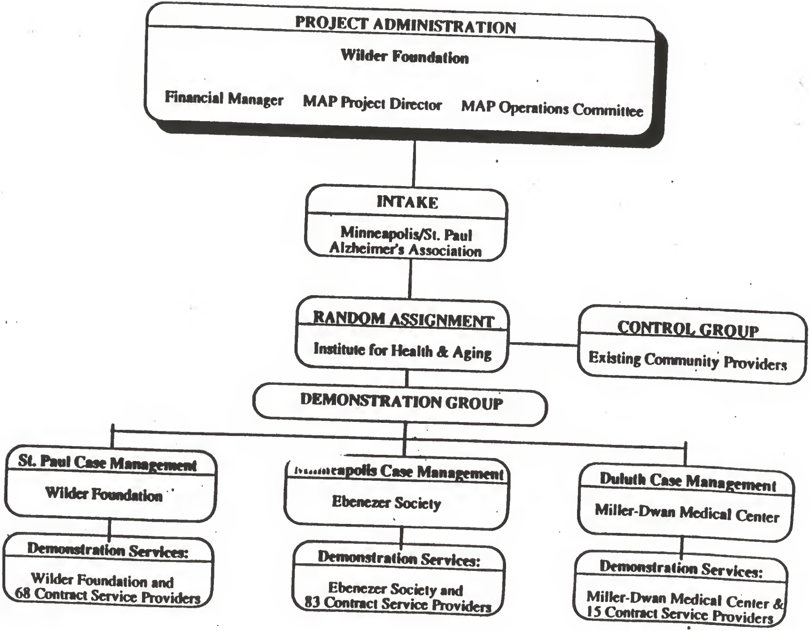

PROJECT ADMINISTRATION
Wilder Foundation
Financial Manager
MAP Project Director
MAP Operations Committee
INTAKE
Minneapolis/St. Paul Alzheimer's Association
RANDOM ASSIGNMENT
Institute for Health & Aging
CONTROL GROUP
Existing Community Providers
DEMONSTRATION GROUP
St. Paul Case Management
Wilder Foundation
Minneapolis Case Management
Ebenezer Society
Duluth Case Management
Miller-Dwan Medical Center
Demonstration Services:
Wilder Foundation and 68 Contract Service Providers
Demonstration Services:
Ebenezer Society and 83 Contract Service Providers
Demonstration Services:
Miller-Dwan Medical Center & 15 Contract Service Providers

Table MN-1

Medicare Alzheimer's Project: Minnesota Demonstration Staffing Patterns

Functional Activities	(Full-Time Equivalent Staff) (April 1991)
Site 1: St. Paul [Wilder Foundation]	
Administrative/Finance	2.28
Case Management	5.24
Research Assistant	.57
Support Staff	1.43
Total	9.52
Site 2: Minneapolis [Ebenezer Society]	
Administrative/Finance	.40
Case Management	7.60
Research Assistant	0
Support Staff	2.15
Total	10.15
Site 3: Duluth [Miller-Dwan Medical Center]	
Administrative/Finance	.20
Case Management	2.30
Research Assistant	0
Support Staff	.50
Total	3.00
Alzheimer's Association	
Administrative/Finance	.25
Case Management	2.42
Research Assistant	.28
Support Staff	1.00
Total	3.95
TOTAL STAFF	**26.62**

Service Environment

The Community Long Term Care Service System

Two of the consortium's catchment areas–the greater St. Paul area and the greater Minneapolis area–are generally considered by the service provider community to be resource rich. Duluth and its surrounding environs, on the other hand, is a rural area with fewer resources. Table MN-2 summarizes each of the three Minnesota catchment areas by scoring community-based services according to their availability, accessibility, and quality of care. The scores were obtained from knowledgeable spokespersons in each service area. While the scores for both the Minneapolis and St. Paul area were relatively high–166 at each site out of a total possible score of 225, the two catchment area service systems were reported to have different strengths. In Minneapolis, the highest service scores were obtained for specialized living arrangements and special purpose services such as day health care. In the St. Paul area, the highest service scores were obtained for home support services, home health services, and integrative services such as information and referral and geriatric assessment. Across all the service categories (integrative services, home health care, home support services, special purpose services, and living arrangements) the Duluth service area scored lower on availability, accessibility, and quality, and was noticeably without two types of service–geriatric assessment and intermediate care facilities. On the other hand, the Duluth area is also notable with respect to its model program for residential care which provides foster care specifically targeted to persons with Alzheimer's disease. The need for this type of care, however, reportedly outweighs its current availability in the Duluth area.

Services Provided By Consortium Members

Three members of the Minnesota Alzheimer's Consortium had extensive prior experience providing a range of community-based services to the elderly: Wilder Foundation; Ebenezer Society; and Miller-Dwan Medical Center. These three organizations provided the majority of the waivered demonstration services. Listed below are the demonstration services provided by each of these consortium members.

Table MN-2

Medicare Alzheimer's Project: Minnesota
Community Spokesperson's Ratings on the Availability, Accessibility, and Quality of the Long Term Care Service System

Service Type	Maximum Points[a]	St. Paul	Minneapolis	Duluth
Integrative Services				
Case Management		6	3	5
Geriatric Assessment		8	7	0
Informational and Referral		9	4	7
Subtotal Points	27	23	14	12
Home Health Care				
Skilled Nursing		9	9	7
Therapies		9	8	6
Social Services		8	6	6
Home Health Aides		7	6	7
Subtotal Points	36	33	29	26
Home Support Services				
Homemaker/Chore Services		7	6	6
Personal Care Services		7	6	6
Meals (home & community)		7	5	6
Adult Protective Services		8	5	4
Mental Health Counseling		7	4	4
Transportation		7	6	6
Subtotal Points	54	43	32	32
Special Purpose Services				
Hospice Care		8	6	6
Day Health Care		5	9	7
Social Day Care		0	9	7
Respite Care		4	6	4
Training for Informal Caregivers		5	6	6
Support Services for Informal Caregivers		9	6	5
Subtotal Points	54	31	42	35
Living Arrangements				
Senior Citizens Housing		9	9	4
Congregate Housing		6	9	5
Board and Care/Residential Care		6	9	5
Foster Care		3	4	5
Intermediate Care Facility		6	9	0
Skilled Nursing Facility		6	9	6
Subtotal Points	54	36	49	25
TOTAL POINTS[c]	225	166	166	130

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[a] Each service type was ranked on a scale of 0 to 3 on the dimensions of availability (0=None, 1=Low, 2=Medium, 3=High) accessibility ((0=None, 1=Low, 2=Medium, 3=High) and quality (0=None, 1=Low, 2=Medium, 3=High). The service score for each service type could range from 0 to 9. The maximum service points within service subgroups and the total possible points across all long-term care services within a catchment area are shown in column 2.

[b] In catchment areas serving more than one county, the ratings for each county were totaled and then an average score was calculated.

Ebenezer Society

Skilled Nursing
Physical Therapy
Occupational Therapy
Home Health Aide
Homemaker/Personal
Medical Supplies
Consumable Care Goods
Companion
Adult Day Care
Home Delivered Meals
Adaptive & Assistive Equipment
Durable Medical Equipment
Mental Health
General Chore (security locks door alarms, ramps, etc.)
Transportation
Family Counseling
Companion For Education

Wilder Foundation

Skilled Nursing
Physical Therapy
Occupational Therapy
Home Health Aide
Homemaker/Personal-Care
Chore
Companion
Transportation
Adult Day Care
Home Delivered Meals
Companion for Education

Generations

Home Health Aide
Adaptive Equipment
Medical Supplies
Consumable Care Goods
Companion
Transportation

Service Provider Contracts

At each location, the consortium's sponsoring agency (Wilder Foundation, Ebenezer Society, Miller-Dwan Medical Center) was the primary and "preferred" provider of services. When possible one of the consortium agencies will provide the services, but there are a number of circumstances where subcontracts are negotiated with agencies outside the consortium. The primary reasons for subcontracting are: the sponsoring agency does not offer the service; the client already has an ongoing relationship with another provider; the client lives in an area where the service is geographically more accessible through another provider; subcontracting made it possible to more quickly access services for clients; and subcontracting to maintain the referral relationship with a service provider. Case managers are given a great deal of freedom in determining the appropriate service provider for each client. The project director for each location is responsible for negotiating the contracts needed within the catchment area. Generally, the demonstration project is matching each service provider's prevailing rate. However, several of the project directors have negotiated slightly reduced rates for some services.

The one difference which stands out between the catchment areas with respect to service provider contracts is the actual number of contracts at each location. At the end of April 1991, Miller-Dwan Medical Center had six service provider contracts, Wilder Foundation had 68 service provider contracts and Ebenezer Society had 83 outside service provider contracts. A fair number of the subcontracts negotiated through Ebenezer and Wilder are subcontracts for a provider to service one individual in the project. The case managers are responsible for quality control with all service providers. The Case Management Supervisor has developed a project-wide Quality Assurance Program for the demonstration and oversees the larger subcontracts.

Outreach and Enrollment

Program Census

The catchment area served by the consortium encompasses six Minnesota counties including urban, suburban, and rural areas. There are an estimated 227,605 non-institutionalized elderly in the catchment area. Under the assumption that 4 percent of the elderly would be cognitively impaired as a result of Alzheimer's or related dementias, it was estimated that 9,104 individuals would be eligible for the demonstration.

The Minnesota Alzheimer's Consortium's initial project census was 720 (360 treatment group clients and 360 control group members). The census goals were subsequently raised to 840 for the initial caseload build-up phase which ended April 30, 1991. At the end of April 1991, the demonstration had 823 active clients (412 treatment group clients and 411 control group members). From the outset of the demonstration, the consortium has been successful with its outreach and enrollment. Enrollment during the first six quarters of the demonstration averaged between 66 and 79 new clients per month (with the exception of the summer quarter when enrollment slowed to an average of 47 new clients per month).

Difficulties Encountered Reaching Enrollment Goals

Although the Minnesota Alzheimer's Consortium was able to maintain its projected number of study members throughout the caseload build-up phase, it was not without a considerable amount of effort. Several factors made it more difficult than anticipated to reach and maintain enrollment goals.

When the project initially began enrolling clients in December of 1989, it was 12 months after the first local announcement about the consortium being awarded the research and demonstration project. At that time, a "waiting list" of applicants was started and maintained. When enrollment began in December, 46 percent of the original waiting list was no longer eligible because the applicant had been permanently institutionalized (29 percent), was deceased (9 percent), or was found to have an ineligible diagnosis based on the physician referral form (9 percent).

In addition, throughout the client caseload build-up phase, almost one out of three beneficiaries and their families to whom an Application Form was sent did not complete the application process. Table MN-3 shows the number and proportion of cases who terminated during the application process and the reason for termination by quarter. The reasons for noncompletion of the application process have been fairly consistent over time once the original waiting list was processed which was approximately March of 1990. Almost one fourth (23 percent) of the applications were terminated because the client permanently entered a nursing home between the time the Application Form was requested and a follow-up call was made by Intake Workers (generally not more than a two week period). Another 7 percent of the applications died before the application process was completed. Other less frequent reasons for non-completion of the application process were: client did not have Medicare Part A and Part B coverage which was a demonstration requirement (5 percent); the client was found to have an ineligible dementia diagnosis (2 percent); the client was already receiving services from another service provider which effectively duplicated the demonstration services (2 percent); and a previous request for an application had already been requested/processed for the same client. Of particular interest was the proportion of applications which were not completed because the family and/or the client was not interested after receiving an application packet (45 percent of all non-completed applications). The two primary reasons reported under the "not interested" category were the potential client's family members could not all agree about participation in the demonstration or the potential client did not want to be in the project. At the end of June 1991, there had been a total of 1,569 application requests for the demonstration; of these applications 405 were not completed. Thus, for every two applicants that entered the demonstration there was a third applicant who either chose not to join the demonstration or was found ineligible based on the demonstration's eligibility criteria.

Other factors impeding rapid client enrollment in Minnesota were: a) physicians were slow to return the Physician Referral Forms; b) families were slow to decide if an applicant and the family actually wanted to participate in the demonstration; and c) there was a three month period in the summer when referrals and applications dropped substantially presumably due to vacations.

In addition, as the project progressed the attrition rate among the demonstration clients was also substantially higher than expected and the consortium had to further increase its outreach efforts to make up for these unanticipated losses in the sample size. The original research design estimated that each site would need to replace 15 percent of its caseload because of attrition due to death, permanent institutionalization, refusal to continue to participate in the project, etc. During the caseload build-up phase of the study sample attrition was substantially higher than the original projections. At the end of April 1991, 23 percent of the study sample had already attrited from the study. The primary reasons for attrition were permanent placement in a nursing home and death.

Table MN-3

Medicare Alzheimer's Project: Minnesota
Reason for Termination During the Application Process by Quarter
(January 1990 through June 1991)

REASON	1990								1991				TOTAL	
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Outside of Catchment Area	1	2	2	2	3	5	1	1			2	2	9	2
Ineligible Diagnosis	2	4	3	4	3	5	2	2	2	2	5	5	17	4
Did Not Have Medicare Part A and Part B	5	11	5	6	5	7	3	3	1	1	3	4	22	5
Unwilling to Consider Co-Payment														
Refused to Sign Consent Form														
Refused to Accept Possibility of Control Group Assignment														
Found to be in Case Managed/ Duplicate Provider System	1	2	3	4	2	3			1	1	3	4	10	2
Refused to Comply with Demonstration Requirements[a]	3	7	1	1									4	1
Institutionalized	20	45	25	30	16	23	19	20	13	13	16	20	109	23
Died	8	18			4	6	2	2	11	11	3	4	28	6
Physician Failed to Return Physician Form														
Could Not Locate for Intake Interview														
Duplicate Applicant	5	11	5	7	5	7	11	12	11	11	13	16	50	11
Not Interested[b]			38	46	30	44	56	60	61	61	37	45	222	47
TOTAL	45	100	82	100	68	100	94	100	100	100	82	100	471	100

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] E.g., intake interview, follow-up interviews, case management, etc.

[b] The two primary reasons reported under the "not interested" category were the client's family members could not all agree about participation or the potential client did not want to be in the project.

Even with these obstacles the Minnesota Consortium consistently maintained the highest enrollment among all the sites throughout the caseload build-up phase of the demonstration. While the consortium used newspaper ads as well as radio and television to advertise the project, it attributes its successful outreach efforts to two principal factors. First, by placing responsibility for program outreach and enrollment with the Minneapolis/St. Paul chapter of the Alzheimer's Association, the consortium had a "natural legitimizer" with the consumer as well as many other referral sources, i.e., other service providers in the community. Second, each of the three primary service provider agencies (Wilder Foundation, Ebenezer Society, and Miller-Dwan Medical Center) had long-standing reputations as providers of quality services for seniors and others with special needs. In general, in the Minneapolis/St. Paul area, professionals in health care related fields are accustomed to rather extensive inter-agency networking and the system is not "turf-ridden." Evidence of the level of community support was found in the number of different referral sources—more than 110 by June of 1990. Finally, the overall approach to the entire outreach effort was designed and implemented as a "friendly, calm, supportive approach" or the antithesis of the "hard sell" approach. These three factors, according to the site, have greatly enhanced the project's ability to maintain and exceed its original enrollment goals.

Case Management Services

Compliance with the Case Management Model

The Case Management Model is one of the primary interventions being tested under the demonstration. Two distinct case management models were being tested: Model A sites were testing a case manager-to-client ratio of 1:100; Model B sites were testing a case manager-to-client ratio of 1:30. Minnesota is a Model B site. To help ensure that each site maintained the appropriate case manager-to-client ratio during the caseload build-up phase of the demonstration, the sites were required to provide monthly reports on the amount of time each case manager was spending on case management related activities and the number of active cases for each case manager. With this information it was possible to monitor the case manager-to-client ratio to determine if the project was complying with the Model B criteria of one case manager per 30 clients. The sites were allowed a 5 percent variance above or below the client-to-case manger ratio during the caseload build-up phase due to addition of clients, transitions in cases, addition of staff, etc. For the Model B sites, this variance could range from 28 and 32 active cases per case manager and not be out of compliance with the Model B criteria (e.g., new cases coming on; clients terminated due to death or institutionalization, etc.).

To be in compliance with the 1:30 case management model in the Model B sites, the case managers should be spending on average between 5 and 5 1/2 hours per month per active client. The data in Table MN-4 show that during the first two quarters of the demonstration at all three locations, the case manager-to-client ratio was even lower than 1:30; each case manager was spending more than 5 1/2 hours per client per month. The project did not consistently comply with the case management model until January 1991, and even after that period of time, there are several months where the case manager-to-client ratio is either somewhat high or low depending on site location.

Case Management Activities

Case managers at each of the three locations in Minnesota were spending similar proportions of their time performing various activities (see Table MN-5). At each of the sites, the majority of the case managers' time (approximately 25 percent) was spent developing the initial care plan, arranging for services and costing the initial care plan. Other activities accounting for major portions of the case managers' time were: service monitoring and follow-up (ranging from 17 to 32 percent); local travel (6 to 13 percent); record keeping (8 to 13 percent); and in-service training for the case managers (4 to 7 percent of the case managers total time in a typical week). Smaller proportions of the case managers time were spent on the initial in-home assessment, case conferences, caregiver education and training, administrative matters, outreach and intake, and public relations.

Demonstration Service Utilization Patterns

During the caseload build-up phase of the demonstration, the number of active clients rose steadily at each of the sites. As shown in Table MN-6 during the second quarter of 1991, the St. Paul site averaged 173 active clients per month; the Minneapolis site averaged 216 active clients per month, and the Duluth site averaged 66 active clients per month.

Of particular interest was the relatively high proportion of client caregivers who were electing to use only the case management services offered by the demonstration. For these clients and their caregivers there were no direct services being provided other than case management; the percentages ranged from 8 to 25 percent depending on the quarter observed. The observed pattern was hard to explain. After the first quarter of the demonstration, there was a steady decline in the proportion of clients and their caregivers electing to use only case management services, then during the first quarter of 1991, the proportion of clients and caregivers using only case management services began to rise again.

The case managers have suggested the following factors impact service utilization patterns. Some of the clients are newly diagnosed and do not as yet require additional services. Some families are reluctant to accept services. In some cases there is a discrepancy between what the client/caregiver think they need and what the case manager and program have to offer. For example, the case manager might think day care would be the best service option for a client, but the effort required by

Table MN-4

Medicare Alzheimer's Project: Minnesota
Compliance with the Model B Case Manager to Client Ratio of 1:30*

Month	Case Manager to Client Ratio[a]		
	St. Paul	Minneapolis	Duluth
February 1990	1:12	1:11	1:16
March 1990	1:17	1:20	1:28
April 1990	1:18	1:24	1:32
May 1990	1:21	1:20	1:25
June 1990	1:23	1:20	1:19
July 1990	1:23	1:31	1:21
August 1990	1:23	1:22	1:21
September 1990	1:28	1:28	1:30
October 1990	1:26	1:22	1:27
November 1990	1:29	1:22	1:30
December 1990	1:35	1:28	1:33
January 1991	1:26	1:27	1:27
February 1991	1:34	1:31	1:34
March 1991	1:28	1:39	1:31
April 1991	1:30	1:30	1:22
May 1991	1:31	1:31	1:23
June 1991	1:35	1:38	1:30

Source: Demonstration Project's Monthy Progress Reports to HCFA

[a] The average case manager to client ratio was derived by dividing the total hours each case manager spends on case management activities each month by the number of clients assigned to the case managers that month. The average hours spent per case managed client were then converted to a ratio by dividing the number of hours per client by the total hours worked in an average month (i.e. 168 hours). In the Model B projects, with a 1:30 case manager-to-client ratio, each client should receive approximately 5.5 hours of case management per month.

* The sites were allowed a 5% variance above or below the case manager-to-client ratio during the caseload build-up phase due to additions of clients, transitions of cases, additions of staff, etc. For the Model B sites, this variance could range from 28 to 32 clients per case manager and not be out of compliance with the Model B criteria.

the caregiver to get the client ready for day care may outweigh the potential benefits According to the case managers, one of their primary roles is to build trust and rapport with the caregiver so that, as the disease progresses and the service needs increase, the caregiver will be willing to accept services.

Table MN-5

Medicare Alzheimer's Project: Minnesota

Activity	Percent Time Spent in Each Activity[a]		
	St. Paul	Minneapolis	Duluth
Outreach and Intake	2.8%	2.6%	2.6%
Initial Assessment	5.8%	2.1%	8.4%
Initial Care Planning/Service Arrangement and Costing of Care Plan	22.2%	22.3%	24.8%
Case Conferences	4.9%	7.2%	6.7%
Service Monitoring/Follow-up	17.6%	32.1%	17.3%
Caregiver Education and Training	3.3%	6.5%	6.7%
Public Relations	1.1%	1.3%	.1%
Administrative/Supervisory Meetings, Reports	5.8%	3.5%	7.9%
Record Keeping/Data Entry	22.7%	8.6%	7.9%
Local Travel	6.0%	10.2%	12.5%
Other	7.2%	3.5%	6.2%
TOTAL	99.4%	99.9%	101.1%

[a] Each case manager completed a time study allocating the total number of hours he/she typically spends during a week in various activities. The Time Study was completed in the Summer of 1990, during the case load build-up phase of the demonstration.

Minnesota
Services Use Patterns by Quarter
(March 1990 through June 1991)

Service Use	1990								1991			
	1st Qtr [a]		2nd Qtr		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
St. Paul												
Average Number Active Treatment Clients per Month	46	100%	67	100%	89	100%	117	100%	143	101%	173	100%
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	28	61%	42	74%	66	63%	90	77%	102	72%	127	73%
Average Number Treatment Clients Receiving Case Management Only	18	39%	17	25%	16	18%	18	15%	30	21%	36	21%
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	NA[b]		8	12%	7	8%	9	8%	11	8%	10	6%
Minneapolis												
Average Number Active Treatment Clients per Month	50	100%	89	100%	124	100%	161	100%	197	100%	215	100%
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	28	56%	62	70%	98	79%	129	80%	155	79%	170	79%
Average Number Treatment Clients Receiving Case Management Only	22	44%	24	27%	22	18%	26	16%	34	17%	39	18%
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	NA[b]		3	3%	4	3%	6	4%	8	4%	6	3%
Duluth												
Average Number Active Treatment Clients per Month	21	100%	30	100%	39	100%	49	100%	57	100%	65	100%
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	15	71%	23	79%	34	87%	37	76%	47	82%	52	80%
Average Number Treatment Clients Receiving Case Management Only	6	29%	5	17%	4	10%	9	18%	8	14%	11	17%
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	NA[b]		2	7%	1	3%	3	6%	2	4%	2	3%

[a] Figures represent the month of March 1990 only. Breakdowns by location were not available for January and February.
[b] NA = Data not available.

CINCINNATI, OHIO - CINCINNATI AREA SENIOR SERVICES, INC.

History and Sponsorship

The Medicare Alzheimer's Disease Demonstration in the greater Cincinnati region of Ohio is a cooperative effort of a consortium of five Cincinnati area health and social service providers: Cincinnati Area Senior Services (CASS); Senior Citizens of Northern Kentucky (SCNK); United Home Care (UHC); the Greater Cincinnati Chapter of the Alzheimer's Association; and the University of Cincinnati Medical Science Center.

CASS, has primary responsibility for overseeing the organization, administration, and conduct of the demonstration. The largest and oldest private non-profit agency in Hamilton County serving an exclusively older population, CASS currently provides in-home assessments, home delivered meals, financial management, case management for homebound individuals, adult day care, shared housing, multi-purpose senior centers, and adult protective services.

SCNK, a non-profit organization founded in 1962, serves older people throughout an eight county Northern Kentucky area. SCNK joined the consortium in order to insure a catchment area large enough to meet the project's target enrollment and in order to include families in the demonstration who live in Kentucky but work in Ohio. Services provided by SCNK include: meals on wheels, transportation, homemaker, lifeline, adult protection, home repair/weatherization, nursing home ombudsman, senior centers, Retired Senior Volunteer Program, adult day care, and information and referral.

UHC, a Medicare/Medicaid certified non-profit agency, provides homemaker, personal care, visiting nurse, chore and respite care services in ten counties in Ohio and Kentucky. UHC also has a respite care program specifically designed to serve clients with Alzheimer's disease.

The Cincinnati Alzheimer's Association Chapter, founded in 1983, focuses on education and family support programs including a network of 14 family support groups, a quarterly newsletter, and working with area service providers who can assist Alzheimer's families. For the demonstration, Alzheimer's Association provides educational and support services for project staff and families of clients.

The University of Cincinnati Medical Science Center, through the College of Medicine and the College of Nursing and Health, has developed a number of specialized programs related to the care of patients with dementia, including an Alzheimer's Research Center and an Evaluation and Treatment Center with an experienced geriatric medicine, nursing, social work, and psychiatry faculty. The participation of the medical center provides the demonstration access to expert clinical consultations for treatment group clients, if needed. In addition, faculty provide consultation and education programs to both the project staff and the formal and informal caregivers of the clients.

A Demonstration Advisory Committee, composed of key representatives from each of the five consortium-member organizations, guides the implementation of the project. The consortium of agencies felt that CASS was the most appropriate and experienced case management agency to serve as the host agency for the demonstration. Demonstration project staff are employees of CASS with the project operating as a separate division of the organization.

The five members of the consortium viewed the demonstration project as an opportunity to: (a) identify the strengths of the participating organizations with regard to working with Alzheimer's families; (b) establish closer working relationships between the five consortium members; (c) develop innovative outreach efforts that would identify previously unidentified victims of Alzheimer's disease and related disorders; (d) develop needed service packages without the usual financial limitations; and (e) develop cost-effective strategies for caring for clients with progressive dementia and their families.

Intraorganizational Structure

The program operates out of one central office building which also houses the lead consortium agency, CASS, as well as the greater Cincinnati Alzheimer's Association. The office is located near downtown Cincinnati within four miles of all consortium members' offices. All administrative, financial, outreach and intake, and case management activities are performed out of the central office.

Figure OH-1 is a chart identifying overall responsibility for performance of key project functions. Program administration, financial management, intake and case management activities are all performed by project staff specifically hired for the demonstration but working under the CASS umbrella organization. Direct services (e.g. home care, companion) are provided under contract by either consortium members or other service provider agencies in the area.

Program Staffing

Table OH-1 shows the demonstration program staffing pattern when the program reached its original enrollment goal of 306 active treatment group clients on April 30, 1991. The total number of demonstration staff was 20. There were four FTE administrative staff, including the project director and the case management supervisor; a business manager, and a data entry clerk. There were 2.5 FTE outreach and intake staff, 10 FTE case managers, and one .5 FTE to conduct education and training primarily for the case managers. There were three FTE support staff person, including one administrative assistant, a secretary, and a receptionist.

Figure OH-1

Medicare Alzheimer's Project: Ohio
Responsibilities for Primary Project Functions

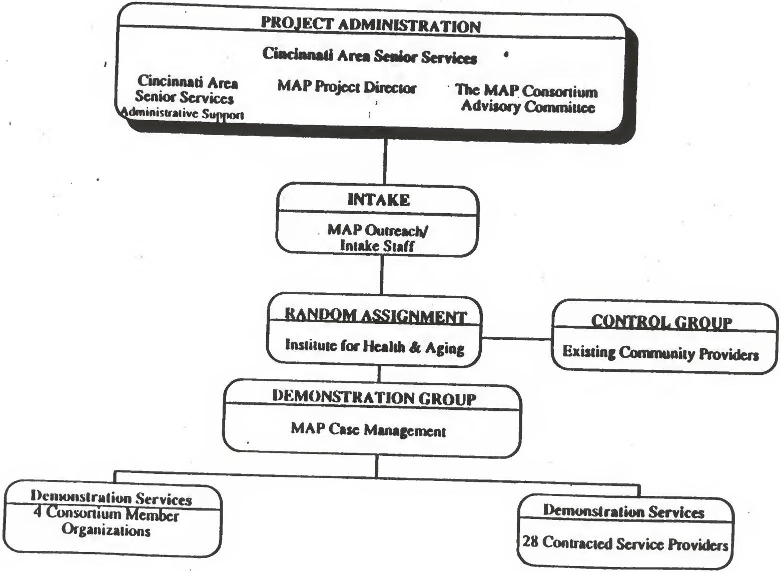
PROJECT ADMINISTRATION
Cincinnati Area Senior Services
Cincinnati Area Senior Services Administrative Support
MAP Project Director
The MAP Consortium Advisory Committee
INTAKE
MAP Outreach/ Intake Staff
RANDOM ASSIGNMENT
Institute for Health & Aging
CONTROL GROUP
Existing Community Providers
DEMONSTRATION GROUP
MAP Case Management
Demonstration Services
4 Consortium Member Organizations
Demonstration Services
28 Contracted Service Providers

Table OH-1

Medicare Alzheimer's Project: Ohio
Demonstration Staffing Patterns

Functional Activities	(Full-Time Equivalent Staff) (April 1991)
Administrative/Finance	4.00
Outreach/Intake	2.50
Case Management	10.00
Education/Training	.50
Research Assistant	0
Support Staff	3.00
TOTAL STAFF	**20.00**

Staff Experience

The senior staff of the project included the project director and the case management supervisor, who both had many years of experience working in community based health and/or social service settings. Two of these key staff also had a family member with Alzheimer's disease. The education and training manager brought vast professional experience to the project, as well as personal experience caring for a family member with Alzheimer's.

Beyond this, the other staff including intake workers and case managers came from a broad range of backgrounds including home health agencies, senior centers, and the clergy. Most of these staff did not have previous experience working with Alzheimer's victims and their families. Throughout the project there has been major emphasis placed on staff education and training specifically oriented towards Alzheimer's issues.

Service Environment

The Community Long Term Care Service System

The catchment area for demonstration services includes all of Hamilton County in Ohio and Kenton, Campbell and Boone Counties in Northern Kentucky. Together the catchment area encompasses the concentrated metropolitan portion of the Greater Cincinnati region. In Ohio, the long term care service delivery system is characterized by numerous non-profit social service agencies with historical roots in the neighborhoods and churches of the 32 cities in the catchment area. The Area Agency on Aging concentrates on senior centers, the Senior Olympics, the Senior Art Show, and employment programs. In 1987, the local Council on Aging also assumed responsibility for managing Ohio's nursing home pre-admission screening program for individuals who are Medicaid eligible. Within the Ohio catchment area, there are many nursing homes and retirement communities. According to community spokespersons, it is not uncommon for Northern Kentucky families to place a family member in an Ohio nursing home because of the long wait and lack of available beds in Kentucky. Over 40 different agencies serve some segment of the elderly population in Hamilton County, Ohio. CASS, the sponsoring agency for the MAP demonstration, is the largest, most comprehensive senior service agency in Ohio offering a broad range of community based services (e.g. senior centers, home meals, transportation). It is also the only private adult protective services agency in the area.

Kentucky has a streamlined system of services to the aging centralized within one agency, SCNK. SCNK is comparable to Ohio's CASS agency in that it provides a broad range of community based services for the elderly. Kentucky also has had a statewide Medicaid waiver program since 1988 which provides in-home services under the direction of certified home health agencies. In addition the state has funded a home care program since 1985 which utilizes independent case management to coordinate services designed to delay nursing home placement. A moratorium on new nursing home beds in Northern Kentucky has made it increasing difficult to place elderly people in institutional care.

In both Ohio and Kentucky, service coordination and referral among agencies were reported to be generally good. Overall, the Greater Cincinnati catchment area served by the demonstration is generally considered by the service provider community to be resource rich. Table OH-2 summarizes the catchment area's service system by scoring community based services according to their availability, accessibility, and quality of care. The scores represent an average score based on the opinions of three knowledgeable spokespersons from the service provider community. The overall score for the MAP project's service provider system was relatively high – 165 out of a total possible score of 225, which suggests a well developed long term care system. The highest service scores were received for home health care, followed by integrative services including information and referral, but most notably geriatric assessment. Additional need for case management services, however, was reported. With respect to Home Support Services, lack of accessibility to services lowered the overall scores for homemaker/chore services, personal care services, mental health counseling and transportation. Special Purpose Services (e.g., day care, respite care) received fairly high scores in each category. The lowest service scores were reported for Living Arrangements with several types of services scoring quite low due to lack of availability and/or accessibility including senior citizens housing, congregate housing, and board and care/residential care which is totally unavailable as a service option in the catchment area. Service scores for intermediate care and skilled nursing home care were in the mid range.

Services Provided by Consortium Members

A number of the services offered under the demonstration are provided by one of the MAP Consortium members. The types of services provided by consortium members are outlined below:

Consortium Member	Type of Service
CASS	Companion/In-Home Respite Home Delivered Meals Adult Day Care Companion/Education & Training
SCNK	Housekeeping/Grocery Shopping Transportation Home Delivered Meals

Table OH-2

Medicare Alzheimer's Project: Ohio
Community Spokesperson's Ratings on the Availability, Accessibility, and Quality of the Long Term Care Service System

Service Type	Maximum Points[a]	Catchment Area Score[b]
Integrative Services		
Case Management		5
Geriatric Assessment		9
Information and Referral		9
Subtotal Points	27	23
Home Health Care		
Skilled Nursing		9
Therapies		9
Social Services		8
Home Health Aides		8
Subtotal Points	36	34
Home Support Services		
Homemaker/Chore Services		5
Personal Care Services		4
Meals (home & community)		8
Adult Protective Services		9
Mental Health Counseling		6
Transportation		4
Subtotal Points	54	36
Special Purpose Services		
Hospice Care		7
Day Health Care		6
Social Day Care		8
Respite Care		7
Training for Informal Caregivers		8
Support Services for Informal Caregivers		7
Subtotal Points	54	43
Living Arrangements		
Senior Citizens Housing		4
Congregate Housing		5
Board and Care/Residential Care		0
Foster Care		8
Intermediate Care Facility		5
Skilled Nursing Facility		7
Subtotal Points	54	29
TOTAL POINTS[c]	225	165

[a] Each service type was ranked on a scale of 0 to 3 on the dimensions of availability (0=None, 1=Low, 2=Medium, 3=High) accessibility ((0=None, 1=Low, 2=Medium, 3=High) and quality (0=None, 1=Low, 2=Medium, 3=High). The service score for each service type could range from 0 to 9. The maximum service points within service subgroups and the total possible points across all long-term care services within a catchment area are shown in column 2.

[b] In catchment areas serving more than one county, the ratings for each county were totaled and then an average score was calculated.

[c] Score range = 0 to 255; 0-75 = Poor Long Term Care Service System; 76-150 - Fair Long Term Care System; 151-255 - Well Developed Long Term Care System.

LHC	Skilled Nursing Home Health Aide Homemaker/Personal Care Housekeeping/Grocery Shopping Chore Services Companion/In-Home Respite Companion/Education and Training
Alzheimer's Association	Education and Training
University of Cincinnati Geriatric Evaluation Center	Education and Training

Demonstration Services Provided Under Contract

In addition to consortium members, the following services are provided to demonstration clients under contract with other community service providers:

Service Type	Number of Subcontracts
Adult Day Care	(8 subcontracts)
Home Care	(28 subcontracts)
Meals on Wheels	(2 subcontracts)
Transportation	(2 subcontracts)
Medical Supplies and Equipment	(7 subcontracts)

There are two major reasons for subcontracting for services. First, if a consortium agency does not have the capacity to provide the service, it will be contracted to one of the community providers. Second, depending on the location of the clients home, one of the contractors may be selected as the preferred provider due to geographic proximity (e.g., adult day care).

Outreach and Enrollment

Program Census

The catchment area served by the MAP Demonstration has a heavy concentration of elderly. In 1985, in the Cincinnati Standard Metropolitan Statistical Area, almost 12 percent of the population was over 65. In Hamilton County the population over 65 was 13 percent, and within the city of Cincinnati, 14.5 percent were over age 65. The over 65 population in the Greater Cincinnati area served by SCNK numbered 52,776. In total, the catchment area included 171,972 elderly in four counties. Using a conservative estimate of 4 percent of the population over age 65 with a probable diagnosis of Alzheimer's disease or related disorders, it was projected that the catchment area included approximately 6,878 individuals affected by the disease.

Based on the above estimates, the project proposal emphasized the consortium's confidence in their ability to identify 500 families (250 treatment group and 250 control group members) who would participate in the project. The census goals for the original caseload build-up phase of the project ending April 30, 1991 were subsequently raised to 600 (300 treatment group and 300 control group members). On that date, the project had 303 active treatment group clients and 294 control group members.

Difficulties Encountered Reaching Enrollment Goals

Although the Ohio MAP demonstration was able to eventually meet its projected client census, there were a number of months when the project fell behind its projected census goals. Unanticipated difficulties locating and recruiting eligible clients proved to be a major stumbling block for the demonstration during the caseload build-up phase. Table OH-3 shows the number and proportion of cases who terminated during the application process and the reason for termination by quarter. The reasons for noncompletion of the application process have fluctuated somewhat from quarter to quarter, but there was no clear pattern or trend to the fluctuations. Overall, more than one-fourth (28 percent) of the applications were terminated because the client was permanently placed in a nursing home between the time the Application Form was requested and the Intake Worker made a follow-up call (usually not more than two weeks) with the exception of the first quarter of 1990 when cases who had been placed on the original waiting list were being processed. Another 16 percent of the applicants died before the application process was completed. Relative to the other demonstration sites, a larger proportion of the applicants (14 percent) were ineligible for the demonstration because the person did not have Medicare Part A or B. Eleven percent of the applicants were not eligible because they lived outside of the demonstration's geographic catchment area. Ten percent of the applicants families did not complete the application process because they were no longer interested after reviewing an application packet. Other less frequent reasons for non-completion of the application process were: the client was found to have an ineligible dementia diagnosis (7 percent); the client was already receiving services from another service provider which effectively duplicated the demonstration services (8 percent); the client/family refused to sign the Consent Form (2 percent); and the client/family refused to comply with the demonstration requirements (2 percent).

At the end of June 1991, there were 605 clients enrolled in the demonstration (306 treatment clients and 299 control clients). There had been a total of 1,211 applications for the project; of these 321 applications were not completed. Thus, slightly more than one-fourth (26 percent) of the families who inquired about the project did not eventually become participants.

The Ohio project was unprepared for the low enrollments it experienced during the early stages of the demonstration. Major efforts were undertaken to turn around the low enrollment problem. Outreach became the principal focus of concern with all staff and even advisory board members brainstorming and working on efforts to increase outreach and enrollment while continuing to serve those clients who had already been enrolled in the treatment group.

The entire community (including all of the service providers that were interviewed during the evaluation teams site visit) seemed perplexed by the census problems being faced by the demonstration. Reports were that no stones had been left unturned. The community outreach efforts were reportedly exemplary--with widespread media coverage, numerous public presentations about the program, and wide-spread support among individuals and service provider agencies in the greater Cincinnati area.

Further investigation by the project into some of the original underlying assumptions about the number of eligible individuals in the catchment area revealed new information. Although there were no exact numbers available, it was reported that substantial numbers of retired residents in the catchment area did not qualify for the MAP demonstration because they did not have Medicare. These were people who had never paid into the Social Security System (never employed, self-employed or domestics) and were, therefore, ineligible for Medicare Part A. Another ineligible group were Federal, State, City, County employees (Public Employee Retirement System) or were teachers and academics under the State Teacher's Retirement System with private health insurance. There were also a reportedly substantial number of low-income uninsured elderly who did not have Medicare Part B and therefore did not quality for the demonstration. The site felt that these were the major reasons for the lower than anticipated enrollment in the demonstration project.

Another factor that impacted on the program census was a higher than expected client attrition. In the original study design it was estimated that the demonstration project would need to replace 15 percent of its caseload because of attrition due to death, permanent institutionalization, refusal to continue to participate in the project, etc. Sample attrition from the study has been substantially higher than the original projections. On April 30, 1991, 20 percent of the study sample had attrited from the study. The primary reasons for caseload attrition were permanent institutionalization and death. (For a more detailed description of the evaluation study sample and caseload attrition, refer to the Evaluation Study Design.)

Case Management Services

Compliance with the Case Management Model

The Case Management Model is one of the primary interventions being tested under the demonstration. Two different models were being tested: Model A sites

Table OH-3

Medicare Alzheimer's Project: Ohio
Reason for Termination During the Application Process by Quarter
(January 1990 through June 1991)

REASON	1990								1991				TOTAL	
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Outside of Catchment Area	1	1%	1	5%	4	27%	16	40%	12	17%	1	4%	35	11%
Ineligible Diagnosis	1	1%	1	5%			5	12%	14	19%	3	12%	24	7%
Did Not Have Medicare Part A and Part B	11	7%	3	16%	4	27%	13	32%	10	14%	3	12%	44	14%
Unwilling to Consider Co-Payment					1	7%	1	3%					2	1%
Refused to Sign Consent Form	2	1%			2	13%	1	3%					5	2%
Refused to Accept Possibility of Control Group Assignment											2	8%	2	1%
Found to be in Case Managed/ Duplicate Provider System	19	13%	3	16%					2	3%	3	12%	27	8%
Refused to Comply with Demonstration Requirements[a]			.		2	13%	2	5%	1	1%			5	2%
Institutionalized	62	41%	7	37%	1	7%	1	3%	9	12%	9	36%	89	28%
Died	37	25%	1	5%	1	7%	1	3%	10	14%	3	12%	53	16%
Physician Failed to Return Physician Form											1	4%	1	.3%
Could Not Locate for Intake Interview									1	1%			1	.3%
Duplicate Applicant														
Not Interested[b]	17	11%	3	16%					13	18%			33	10%
TOTAL[c]	150	100%	19	100%	15	101%[c]	40	101%[c]	72	99%[c]	25	100%	321	101%[c]

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] E.g., intake interview, follow-up interviews, case management, etc.

[b] The two primary reasons reported under the "not interested" category were the client's family members could not all agree about participation or the potential client did not want to be in the project.

[c] Percentages greater than or less than 100% due to rounding.

were to maintain a case manager-to-client ratio of 1:100; Model B sites were to maintain a case manager-to-client ratio of 1:30. The Ohio project was a Model B site. To help ensure that each site maintained the appropriate case manager-to-client ratio during the caseload build-up phase of the demonstration, the sites were required to provide monthly reports on the amount of time each case manager was spending on case management-related activities and the number of active cases assigned to each case manager. With this information it was possible to monitor the case manager-to-client ratio to determine if the project was complying with Model B criteria of one case manager to 30 clients.

To be in compliance with the 1:30 case management model in the Model B sites, the case managers should have spent on average between 5 and 5 1/2 hours per month per active client. The data in Table OH-4 show that from the onset of the project through October 1991, the case manager-to-client ratio was within the acceptable range for a 1:30 model. It should be noted that sites were permitted to be slightly over or under the desired ratio by 5 percent (i.e. ranging from 28 to 32 clients per case manager). After that period there was slightly more fluctuation in the ratio. During four of the remaining months of caseload, the case manager-to-client ratios were slightly higher than specified by the model.

Case Management Activities

As shown in Table OH-5, the case managers spent the most of their time on two activities: developing the initial care plan, arranging for services, costing out the care plan, (15 percent), and service monitoring and follow-up of the care plans (36 percent). Two other activities each accounted for an additional 10 percent of the case managers total time—conducting initial home assessments and local travel primarily for completing the home assessments. Less than 10 percent of the case managers' time was spent on outreach and intake (3 percent), case conferences (6 percent), caregiver education and training (2 percent), public relations (3 percent), administrative matters (9 percent), and record keeping (5 percent).

Table OH-4

Medicare Alzheimer's Project: Ohio
Compliance with the Model B Case Manager to Client Ratio of 1:30*

Month	Case Manager to Client Ratio[a]
February 1990	1:25
March 1990	1:34
April 1990	1:28
May 1990	1:28
June 1990	1:30
July 1990	1:33
August 1990	1:30
September 1990	1:32
October 1990	1:40
November 1990	1:36
December 1990	1:39
January 1991	1:42
February 1991	1:40
March 1991	1:38
April 1991	1:36
May 1991	1:36
June 1991	1:40

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] The average case manager to client ratio was derived by dividing the total hours each case manager spends on case management activities each month by the number of clients assigned to the case managers that month. The average hours spent per case managed client were then converted to a ratio by dividing the number of hours per client by the total hours worked in an average month (i.e. 168 hours). In the Model B projects, with a 1:30 case manager to client ratio, each client should receive approximately 5.3 hours of case management per month.

* The sites were allowed a 5% variance above or below the case manager-to-client ratio during the caseload build-up phase due to additions of clients, transitions of cases, additions of staff, etc. For the Model B sites, this variance could range from 28 to 32 clients per case manager and not be out of compliance with the Model B criteria.

Demonstration Service Utilization Patterns

During the caseload build-up phase of the demonstration the number of active clients rose steadily. As shown in Table OH-6, during the second quarter of 1991, the project averaged 306 active clients per month. With respect to service use, as shown in Table OH-6, almost one-fourth of the treatment group clients elected to use only the case management services offered by the demonstration. In other words, there were not utilizing any of the direct services such as homemaker chore or day care. The case managers and project staff reported that a number of complex interrelated factors might explain this service use pattern. Some caregivers felt strongly that only he/she (the caregiver) could provide the best and most appropriate care for the client. Other caregivers wanted to wait until they felt there was a greater need for help; expecting that they would use the demonstration's direct services at some later date. Other caregivers were reluctant to become involved with services that required a co-pay. Finally, there were a number of caregivers who reported that they had tried various community services and the client was unable to adapt to either the provider or the setting (e.g., day care). Data from the second wave of the evaluation will provide some clearer answers to the reasons that clients and/or their caregivers chose not to use the full compliment of demonstration services during the earlier phases of the demonstration.

Table OH-5

Medicare Alzheimer's Disease Demonstration: Ohio
Case Management Activities

Activity	Percent Time Spent in Each Activity[a]
Outreach and Intake	3%
Initial Assessment	10%
Initial Care Planning/Service Arrangement and Costing of Care Plan	15%
Case Conferences	6%
Service Monitoring/Follow-up	36%
Caregiver Education and Training	2%
Public Relations	3%
Administrative/Supervisory Meetings, Reports	9%
Record Keeping/Data Entry	5%
Local Travel	10%
Other	1%
TOTAL	100%

[a] Each case manager completed a time study allocating the total number of hours typically spent during a week in various activities. The Time Study was completed in the Summer of 1990, during the case load build-up phase of the demonstration.

Table OH-6

Medicare Alzheimer's Project: Ohio Services Use Patterns by Quarter (March 1990 through June 1991)

Service Use	1990								1991			
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Average Number Active Treatment Clients per Month	45	100%	86	100%	153	100%	228	100%	270	100%	306	100%
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	35	78%	62	72%	96	63%	150	66%	182	67%	220	72%
Average Number Treatment Clients Receiving Case Management Only	10	22%	20	23%	46	30%	61	27%	77	29%	79	26%
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	NA[a]		4	5%	12	7%	16	7%	11	4%	8	3%

[a] NA = Data not available for the 1st Quarter of 1990.

PARKERSBURG, WEST VIRGINIA - WOOD COUNTY SENIOR CITIZENS ASSOCIATION, INC.

History and Sponsorship

Two agencies sponsor the Medicare Alzheimer's Disease Demonstration in West Virginia. One is the Wood County Senior Citizens Association (WCSCA) in Parkersburg, and the other is the Family Service - Upper Ohio Valley, in Wheeling, West Virginia. WCSCA began the initial enrollment period serving one rural county area encompassing the county seat of Parkersburg (Wood County) on the far northwestern border of the state. Family Service served three rural counties (Ohio County, Marshall County, and Brooke County). These are located in the panhandle of northwestern West Virginia (situated between Pennsylvania and Ohio along the Ohio River). The service areas were expanded five times during the initial enrollment build-up phase.

WCSCA was established in 1975 as a senior recreation program. Over the years, the programs have been expanded to encompass recreation, personal and home health care, and other support services including transportation, homemaker services, escort, shopping, health monitoring, information and referral, visiting reassurance and outreach, and adult day care programs. WCSCA facilities also house the Older Americans Act III-C Nutrition Program for the elderly. WCSCA serves as the focal point for most senior services in Wood County. The Association coordinates social activities, special programs, and health services at 12 satellite centers and 7 nutrition sites throughout the county. In 1985, WCSCA became one of the first agencies in the state to develop and implement an adult day care program for the frail elderly. Although the adult day care program is not limited to patients with Alzheimer's disease or related disorders, the program offers specialized activities, supervision and programming for these clients. In 1989, WCSCA completed renovations within its senior facility to provide special housing for older adults in jeopardy of institutionalization.

Family Service -Upper Ohio Valley is a non-profit social service agency established in 1909. In addition to being a licensed mental health facility, it is an accredited member of Family Service Association of America, National Foundation for Consumer Credit Counseling and United Way of the Upper Ohio Valley and certified by Housing and Urban Development as a Comprehensive Housing Counseling Agency. Family Service has two divisions of programs, the Senior Services division and the Counseling division. Senior Services represents a diverse and highly specialized system of program and services. For example, in addition to providing the numerous support services offered by Wood County, Family Service has drawn upon its counseling division to provide group and individual psychotherapy, family life education, conservator services, housing counseling, and debt counseling and disbursement services to the elderly.

With over 90 years of community service, 15 of which have been specific to the senior population, and with specialized programs such as Adult Protective Services, adult day care, counseling, conservator services, Family Service has gained extensive experience with the community-based long-term care population.

There was no formal relationship between WCSCA and Family Service prior to the request for proposal RFP from HCFA but this was the first joint venture between the agencies. Wood County originally contacted Family Service to explore a combined application. After discussions began between the agencies, information and support were sought by the two agencies from other social and health providers within the two catchment areas. For example, the Mid-Ohio Valley Health Department, which is a regional health care provider serving a six county area in the western portion of West Virginia that provides home health services, personal care/homemaker services, and operates a hospice program was very supportive of the proposal and provided statistics to the two agencies for the development of the proposal. It was eventually selected as a contract service provider to the demonstration. Similarly, the Ohio County Area Agency on Aging in Wheeling was brought in by Family Service to assist in information gathering, provide background statistics and service information for the proposal, and to help generate support for the program among other local service providers.

The administrative staff at both agencies viewed the proposal as a joint venture with administrative and budgetary responsibilities shared between them. In addition, both agencies realized that they needed a larger catchment area than their individual service areas if they were to meet the demonstration enrollment requirements. The approved proposal established essentially dual service systems in each separate service area. The agencies saw themselves as partners. As a result of the need for one agency to be fiscally and administratively responsible for the program, WCSCA became the lead agency.

Intraorganizational Structure

The demonstration in Parkersburg operates as a separate unit or division within the host agency, the WCSCA. The demonstration Project Director and the Agency Director meet weekly to discuss program issues as a separate unit or division within the agency. The demonstration utilizes the host agency auditor, but they have hired their own lawyer and computer support staff. The demonstration is treated like all other divisions within the agency. Wood County's Director serves the same role for all divisions within the organization: that of oversight, administration and public relations. The director of the demonstration is responsible for the day-to-day management of the program.

In Wheeling, the demonstration is more closely tied into the host agency's other programs. The Wheeling Site Director reports directly to both the host agency Director and to the Demonstration Project Director in Parkersburg. For example, there were some minor start-up problems concerning the integration of the demonstration within the Wheeling agency's In-Home Services Department. There was some friction between the demonstration staff and the staff of the In-Home Services programs due to the disparity in the salaries of the two programs. Although demonstration staff members are paid more than most other agency staff, agency staff are paid more than the minimum wage and most do have bachelor's degrees. In addition, there were some initial problems with the scheduling of services for demonstration clients, and on a few occasions, personal care staff changed care plans without consultation with the case manager. As a result, relations between the demonstration and some of the other programs were difficult during the program development stage. However, these issues were constructively addressed by the Project Director in Parkersburg and the program appears to be functioning smoothly.

Figure WV-1 presents a chart identifying overall responsibility for performance of key project functions for the Medicare Alzheimer's Demonstration, including program administration, financial management, intake, and case management activities. Most staff were hired for the demonstration including two key staff members, the demonstration Site Director (Parkersburg) and the Case Management Supervisor (Wheeling). Two Parkersburg staff were already on staff prior to the demonstration, the Parkersburg case management supervisor and an administrative assistant who was later promoted to case manager. Direct services to clients are provided under contract by the host agencies or by other service provider agencies in the four-county area.

Program Staffing

Table WV-1 shows the demonstration program's staffing pattern when the program reached its original enrollment goal of 120 active treatment clients in April, 1991. The total number of full and part-time demonstration staff members was 17 with a total of 16.1 FTE staff positions. There were 2.98 FTE administrative and finance staff including the project director, case management supervisor, and financial staff at the Parkersburg site and .95 FTE Case Management Supervisor at the Wheeling site. There was 1.24 FTE Outreach and Intake staff in Parkersburg and 1.52 FTE in Wheeling; 3.0 FTE Case Managers at the Parkersburg site and 3.03 FTE in Wheeling. There was a .15 FTE in Parkersburg and .02 FTE in Wheeling to conduct education and

Figure WV-1

Medicare Alzheimer's Project: West Virginia Responsibilities for Primary Project Functions

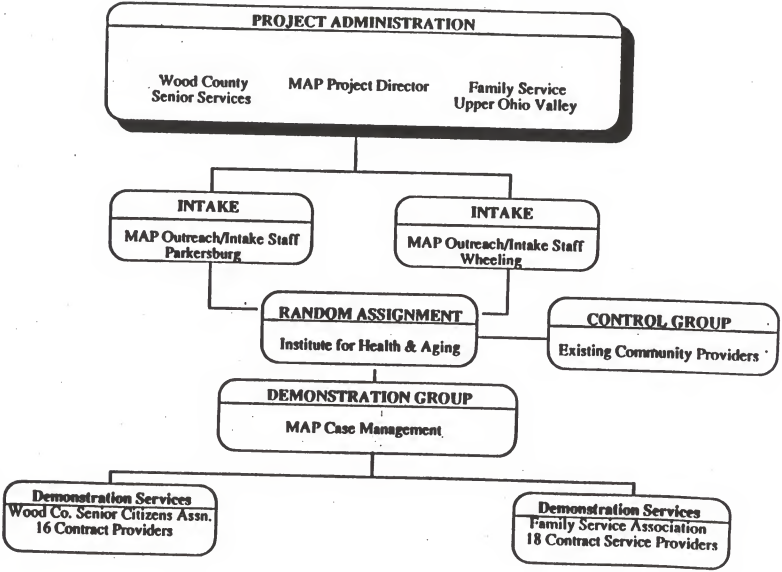
PROJECT ADMINISTRATION
Wood County Senior Services
MAP Project Director
Family Service Upper Ohio Valley
INTAKE
MAP Outreach/Intake Staff Parkersburg
INTAKE
MAP Outreach/Intake Staff Wheeling
RANDOM ASSIGNMENT
Institute for Health & Aging
CONTROL GROUP
Existing Community Providers
DEMONSTRATION GROUP
MAP Case Management
Demonstration Services
Wood Co. Senior Citizens Assn.
16 Contract Providers
Demonstration Services
Family Service Association
18 Contract Service Providers

Table WV-1

Medicare Alzheimer's Project: West Virginia Demonstration Staffing Patterns

Functional Activities	(Full-Time Equivalent Staff) (April 1991)
Site 1: Parkersburg	
Administrative/Finance	2.98
Outreach/Intake	1.24
Case Management	3.00
Education/Training	.15
Research Assistant	0
Support Staff	1.26
Other (Gerontological RN)	.43
Site 2: Wheeling	
Administrative/Finance	.95
Outreach/Intake	1.52
Case Management	3.03
Research Assistant	.02
Education/Training	0
Support Staff	1.00
Other (Gerontological RN)	.52
TOTAL STAFF	**16.10**

City of Belpre, situated across the Ohio River in Washington County, Ohio. In September 1990, Family Service expanded its catchment area to include two new counties; Wetzel County in West Virginia and Belmont County in Ohio. In December 1990, Tyler County in West Virginia was added to the Wood County catchment area and in May 1991, Family Service added Hancock County in West Virginia and the Stubenville metropolitan area in Jefferson County, Ohio. The total catchment area between 12/89 and 5/91 included eleven counties in West Virginia and three counties in Ohio.

As of the 1980 Census, the state of West Virginia has the eighth highest concentration of older persons in the country. Over 12 percent of Wood County's, over 15 percent of Ohio County's, and over 11 percent of Marshall and Brooke Counties' populations are 65 or older. In addition, almost 5 percent of Wood County's, over 6 percent of Ohio County's, and over 4 percent of Marshall and Brooke Counties' populations are 75 or older. Over 13 percent of the population 65 or older in Wood County and almost 29 percent of those 65 or older in Ohio County live below the poverty level while over 15 percent of those 65 or older in Marshall County and almost 14 percent of Brooke County residents 65 or older live below the poverty level. Finally, 80 percent of those 75 or older in Wood County, 63 percent of Ohio County, 65 percent of Marshall and over 70 percent of those 75 or older in Brooke County lived below the poverty level and were living alone.

The long term care service delivery system within the four counties of the West Virginia demonstration catchment area is characterized by few non-profit or for-profit social and health service delivery agencies. The counties are rural, with Columbus, Ohio the closest large metropolitan area, approximately a four hour drive from Parkersburg. Pittsburg, Pennsylvania, the next largest metropolitan area, is a three hour drive from Parkersburg and a one hour drive from Wheeling. The need for nursing home beds is critical in West Virginia since this is the traditional service option for families with an Alzheimer's patient. Few service agencies focus on Alzheimer's and the medical community tends to institutionalize Alzheimer's patients due to the dearth of community-based service options in West Virginia. In some instances, West Virginians travel to Ohio and Pennsylvania to obtain specialized services. This is true both for Wood County and the Wheeling site.

West Virginia, like many states, has a certificate of need process that limits the availability of nursing home beds. Complicating this situation even more, nursing homes have had a "freeze" on the number of beds that can be "booked." Ohio and Pennsylvania tend to have more beds available due to more aggressive pre-admission screening programs that limit the number of elderly admitted to nursing homes and a broader, more comprehensive community-based long term care system.

In Parkersburg, the major community health service provider is the Mid-Ohio Valley Health Department, a regional service provider serving six counties in mid and western West Virginia (Pleasant, Ritchie, Wood, Wirt, Jackson, and Roane counties). It is the only regional health department in the state and the only health department in the state offering a home care program (i.e., personal care). Other services include a home health agency and a hospice program. Although the Parkersburg area is among the top ten within the state in numbers of people served by most programs, there are few case management and/or information and referral services in the county and few special purpose services like adult day health care. Finally, there are no respite care programs for the elderly and few special living arrangement options (such as adult foster care/board and care homes, congregate housing, senior citizen housing, nursing homes).

Since WCSCA is primarily a home and personal care provider, the idea initially was to use the host agency's homemaker service as a major contract provider. However, because the homemaker program was understaffed and because it did not want the responsibility for training or scheduling specifically trained staff to work with the Alzheimer's cases, the decision was made to set up a separate home care department within WCSCA to serve the demonstration clients. This was done during the implementation phase of the project and the program seems to be working well. There were no internal "turf" issues between the two staffs. Additionally, the new program did not affect referrals to the original homemaker program.

The same situation is found in Wheeling and the three counties served by Family Service; that is, there are few service delivery options in northwestern West Virginia. The Wheeling catchment area contains a "panhandle," situated between Pennsylvania and Ohio. Services, especially if the client qualifies for a state or federal program or can pay for it, can be obtained in any of the tri-state counties. Overall, there are access problems in all four counties for Alzheimer's patients in West Virginia. The main barrier is money and the fact that there are few services available for people with Alzheimer's.

On July 1, 1991, three case management agencies in the Wheeling catchment area assumed responsibility for the pre-screening of nursing home admissions. Hospitals in the area refer cases to one of the three agencies who do screening assessments, costing of care plans, and initiation of community services. The clients must be medically eligible for nursing home admission and either be financially eligible for Medicaid or pay for services on a sliding fee scale. The program is the beginning phase of a coordinated access system that will have one focal point of entry.

Table WV-2 summarizes the two demonstration catchment areas by scoring community-based services according to their availability, accessibility, and

Table WV-2

Medicare Alzheimer's Project: West Virginia Community Spokesperson's Ratings on the Availability, Accessibility, and Quality of the Long Term Care Service System

Service Type	Maximum Points[a]	Catchment Area Scores[b]	
		Parkersburg	Wheeling
Integrative Services			
Case Management		4	6.5
Geriatric Assessment		3	5.5
Information and Referral		5	6.5
Subtotal Points	**27**	**12**	**18.5**
Home Health Care			
Skilled Nursing		8	8.0
Therapies		8	8.0
Social Services		8	8.0
Home Health Aides		8	6.5
Subtotal Points	**36**	**32**	**30.5**
Home Support Services			
Homemaker/Chore Services		6	6.0
Personal Care Services		7	4.5
Meals (home & community)		7	4.5
Adult Protective Services		6	4.5
Mental Health Counseling		6	7.0
Transportation		7	4.5
Subtotal Points	**54**	**39**	**31**
Special Purpose Services			
Hospice Care		4	7.5
Day Health Care		2	5.0
Social Day Care		7	5.5
Respite Care		5	5.0
Training for Informal Caregivers		7	4.5
Support Services for Informal Caregivers		7	4.5
Subtotal Points	**54**	**32**	**32**
Living Arrangements			
Senior Citizens Housing		7	8.0
Congregate Housing		4	5.5
Board and Care/Residential Care		4	5.0
Foster Care		3	4.5
Intermediate Care Facility		7	7.5
Skilled Nursing Facility		7	7.5
Subtotal Points	**54**	**32**	**38**
TOTAL POINTS[c]	**225**	**147**	**150**

[a] Each service type was ranked on a scale of 0 to 3 on the dimensions of availability (0=None, 1=Low, 2=Medium, 3=High) accessibility ((0=None, 1=Low, 2=Medium, 3=High) and quality (0=None, 1=Low, 2=Medium, 3=High). The service score for each service type could range from 0 to 9. The maximum service points within service subgroups and the total possible points across all long-term care services within a catchment area are shown in column 2.

[b] In catchment areas serving more than one county, the ratings for each county were totaled and then an average score was calculated.

[c] Score range = 0 to 255; 0-75 = Poor Long Term Care Service System; 76-150 - Fair Long Term Care System; 151-255 - Well Developed Long Term Care System.

quality of care. The scores were obtained from knowledgeable spokespersons in each service area. While the scores for each of the service types is fairly close between the two areas, Parkersburg lacks integrative services (e.g., case management services, information and referral services) while it is slightly better than the three counties served by the Wheeling site in terms of home support services (e.g., homemaker/chore service, personal care services, meals, transportation). Alternatively, the Wheeling area appears to have slightly greater access to integrative services such as case management but less access to home support services. However, overall, the need for social, health, and support services far outweighs their current availability in the West Virginia area.

There are very few services specifically targeted for the Alzheimer's patient in either the Parkersburg or the Wheeling areas. However, most social and health service agencies serving the elderly in the four counties have dementia clients. WCSCA started the first Adult Day Care Program in the area and, while the program serves many age groups, approximately 11 of the over 35 elderly participants were Alzheimer's patients. Family Service also recently established an Adult Day Care program, though it, too, serves the general elderly population not just Alzheimer's patients.

The usual entry point for Alzheimer's and related dementia patients is through the medical community. The AD diagnosis usually occurs in the hospital after an illness episode or accident calls attention to the case. Other entry points are the family physician and Adult Protective Services. Both the hospital and Adult Protective Services are getting advanced stage cases and are likely to refer to nursing homes. Physicians appear to be seeing cases at a much earlier stage in their illness and do refer to community-based services where available. However, most referrals are to nursing homes or other institutional settings and there appears to be some incidents of nursing homes refusing to accept Alzheimer's patients. Finally, there are no respite programs in the Parkersburg or Wheeling areas for the elderly.

Demonstration Service Providers

Each host agency in the West Virginia demonstration is the primary and "preferred" provider of services. Subcontracts have been negotiated with agencies outside the host agencies. The Parkersburg site is contracting with most of the area's social/health providers except for durable medical equipment providers in Wood County where they have negotiated two contracts. In Wheeling, all other providers have been contracted with. Overall, cooperation with other agencies, especially for referral of clients, has been good in both sites. The demonstration staff believe this is a result of the recognition that services for this population are rare and that many service providers in the area do not want to deal with this population.

The primary reasons for subcontracting are: the host agency does not offer the service; the client already has an ongoing relationship with another provider; the client lives in an area where the service is geographically more accessible through another provider; and/or subcontracting enhances the ability of the case manager to effectively broker service on behalf of clients and caregivers. Case managers are given a great deal of freedom in determining the appropriate service provider for each client. The Project Director in Parkersburg and the Agency Director in Wheeling are responsible for negotiating the contracts needed within each catchment area. Generally, the demonstration is matching each service provider's prevailing rate. However, in a few circumstances, the director was able to negotiate a slightly reduced rate for some services. For the most part, the contract agencies had no problems with accepting the liability for bad debt or allowing the demonstration to collect the co-payments or offering employees the special training in working with Alzheimer's and their families.

Two problems were encountered with the service delivery contracts in Parkersburg. One problem was that not all service arrangements were set up as quickly as the case managers needed them. The other problem was the lack of appropriately trained contract agency staff. Thus, service delivery in the early part of the project was about one month behind schedule. In Wheeling, there were the internal conflicts mentioned above.

Services provided by WCSCA include:

- adult day care,
- home delivered meals,
- transportation,
- personal care/homemaker services,
- companion services,
- chore (general and repair/maintenance), and
- caregiver education and training, and
- housekeeping services

Services provided by Family Service-Upper Ohio Valley include:

- adult day care,
- personal care/homemaker,
- housekeeping,
- companion services,
- home delivered meals,
- transportation,
- mental health services,
- family counseling, and
- caregiver education and training.

Wood County had a total of 16 service provider contracts as of April 1991 while the Family Service had a total of 18 service provider contracts. Most of the contracts are for homemaker or personal care services (seven in Parkersburg and six in Wheeling), home health agency, durable medical equipment or home maintenance services.

Outreach and Enrollment

Program Census

The catchment area served by WCSCA (i.e., Wood County) includes primarily rural areas with an estimated population of over 12,000 people 65 or older. The catchment area served by Family Service includes three rural counties (Ohio, Marshall, and Brooke counties) with an estimated 65 and over population of 17,820 (9,430 in Ohio County, 4,880 in Marshall County, and 3,510 in Brooke County). Under the assumption that 4 percent of the elderly would be cognitively impaired as a result of Alzheimer's or related dementias, it was estimated that approximately 480 elderly in Wood County and 713 elderly in the three counties served by Family Service would be eligible for the demonstration.

The West Virginia Alzheimer's Disease Demonstration initial project census was 240 (120 in Treatment and 120 in Control). Each site matched the treatment client census with an equal number of control group clients. The treatment/control group issues are discussed in the research design section of this report.

The original census goals were raised 120 cases in May 1991 (60 Treatment and 60 Control) during the caseload build-up phase of the demonstration. This resulted in the final program census goal of 360 (180 in the Treatment group and 180 in the Control group) to be reached by October 1991. The enrollment figures were expanded to accommodate requests for services that originated in counties bordering the original catchment area counties.

On April 30, 1991, the West Virginia site exceeded its expanded enrollment goals and had enrolled a total of 374 clients (187 treatment clients and 187 control clients). From the outset of the demonstration, both the Parkersburg and the Wheeling sites have been successful with their outreach and enrollment activities.

Difficulties Encountered Reaching Enrollment Goals

For the most part, the West Virginia demonstration was able to meet its projected client census goals throughout the caseload build-up phase. However, there were some periods during caseload build-up when they were slightly behind their projected census. In addition, unanticipated difficulties in locating and recruiting eligible clients arose which required changes in some outreach procedures. Outreach efforts were extended into new counties to aid in increasing enrollment in the Demonstration. The Parkersburg site extended it's catchment area into Pleasants county; Wirt county; Ritchie county (all in West Virginia); and Washington County, Ohio (across the river from Parkersburg). While Family Service-Upper Ohio Valley has extended it's catchment area into Wetzel county and Hancock county (West Virginia) and Jefferson county and Belmont county, Ohio, (across the river from Wheeling). One drawback to this expansion into more rural counties has been an increase in travel time for outreach workers and case managers, as well as the cost of outreach (i.e., mileage/promotion).

When the project initially began enrolling clients in December of 1989, it was a full 13 months after the first local announcement about the demonstration being awarded to WCSCA. At that time, a "waiting list" of applicants was started and maintained. When enrollment finally began in December, a good proportion of those on the waiting list were no longer eligible because the applicant had been permanently institutionalized, was deceased, or was found to have an ineligible diagnosis based on the Physician Referral Form.

Table WV-3 shows the number and proportion of cases who terminated during the application process and the reason for termination by quarter through April 1991. The most frequent reason for termination of application was because the applicant lived outside of the demonstration's catchment area (24 percent). The next most frequent reason for termination was "not interested" (23 percent). Other reasons for termination included: the client had an ineligible diagnosis (17 percent), the applicant did not have Medicare Part A and Part B (13 percent), and/or client had been institutionalized prior to randomization into the study (13 percent). Reasons given for the applicant not being interested included: a lack of response after applications had been sent, applicant changed his/her mind after the application process began, or the applicant only wanted information about Alzheimer's disease.

At the end of April 1991, there had been a total of 528 application requests for the demonstration. Of these applications, 202 were not completed. Of those clients who did enroll in the demonstration, 90 clients had attrited from the study by the end of April 1991 due to institutionalization, death, moved out of catchment area, etc.

Factors impeding rapid client enrollment in West Virginia were: a) physicians were slow about returning the Physician Referral Forms; b) families were slow to decide if they wanted to participate in the demonstration; and c) there were periods when referrals and applications dropped substantially, presumably due to vacations or "snowbirds," i.e., those

Table WV-3

Medicare Alzheimer's Project: West Virginia
Reason for Termination During the Application Process by Quarter
(January 1990 through June 1991)

REASON	1990								1991				TOTAL	
	1st Qtr.		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Outside of Catchment Area	9	31	18	56	14	35	4	12	4	10			49	24
Ineligible Diagnosis	3	11	2	6	2	5	10	29	10	24	7	28	34	17
Did Not Have Medicare Part A and Part B	5	17	1	3	8	20	5	15	3	8	5	20	27	13
Unwilling to Consider Co-Payment														
Refused to Sign Consent Form														
Refused to Accept Possibility of Control Group Assignment														
Found to be in Case Managed/ Duplicate Provider System	1	3											1	1
Refused to Comply with Demonstration Requirements[a]	1	3	1	3					1	2			3	1
Institutionalized	3	11	6	20	5	13	3	9	5	12	4	16	26	13
Died	1	3	2	6	1	2			1	2	1	4	6	3
Physician Failed to Return Physician Form														
Could Not Locate for Intake Interview	2	7					1	3	1	2			4	2
Duplicate Applicant							2	6	1	2	3	12	6	3
Not Interested[b]	4	14	2	6	10	25	9	26	16	38	5	20	46	23
TOTAL[c]	29	100	32	100	40	100	34	100	42	100	25	100	202	100

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] E.g., intake interview, follow-up interviews, case management, etc.

[b] The two primary reasons reported under the "not interested" category were the client's family members could not all agree about participation or the potential client did not want to be in the project.

[c] Percentages greater than or less than 100 due to rounding.

people leaving the state for warmer weather during the winter. Even with these obstacles, the West Virginia demonstration maintained a high level of enrollment throughout the caseload build-up phase of the demonstration. The demonstration used newspaper and television advertising, outreach activities that included staff speaking to physicians, hospital and nursing home personnel, social service agency staff, senior groups, and home health and personal care staff. Success in outreach is attributed to the hard work and diligence of the outreach staffs at both sites.

Case Management Services

Compliance with the Case Management Model

The Case Management Model is one of the primary interventions being tested under the demonstration. To help ensure that each site maintained the appropriate case manager-to-client ratio during the caseload build-up phase of the demonstration, the sites were required to provide monthly reports on the amount of time each case manager was spending on case management related activities and the number of active cases for each case manager. With this information it was possible to monitor the case manager-to-client ratio to determine if the project was complying with the Model B criteria of one case manager per 30 clients. It was decided by HCFA that the demonstration sites could fluctuate 5 percent of the case manager-to-client ratio during the caseload build-up phase due to additions of clients, transitions in cases, addition of case management staff, etc. For Model B sites, this variance could range between 28 and 32 clients per case manager and not be out of compliance with the Model B criteria.

To be in compliance with the 1:30 case management model in the Model B sites, the case managers should be spending, on average, between 5 and 5 1/2 hours per month per active client. The data in Table WV-4 show that, during the client build-up phase, the two West Virginia locations had vastly different case manager-to-client ratios. During caseload build-up, the Parkersburg site consistently averaged a higher than 1:30 case manager-to-client ratio while the Wheeling site fluctuated above and below the Model B ratio.

Based on the data in Table WV-4, the case managers in Parkersburg and Wheeling were spending less than the 5 to 5 1/2 hours per client as required in the model. Case manager-to-client ratios in Parkersburg ranged from a low of 1 case manager to 20 clients in February 1990 to a high of 1 to 61 clients in March 1991. The Parkersburg site averaged a case manager-to-client ratio of 1 to 45. Case manager-to-client ratios in Wheeling ranged from a low of 1:11 in February 1990 to a high of 1:47 in November, 1991. By June 1991, the Wheeling site was slightly under the 1-to-30 ratio. This meant that the case managers in Wheeling were spending, on average, slightly more than

Table WV-4

Medicare Alzheimer's Project: West Virginia
Compliance with the Model B Case Manager to Client Ratio of 1:30*

Month	Case Manager to Client Ratio[a]	Case Manager to Client Ratio[a]
	Parkersburg	**Wheeling**
February 1990	1:20	1:11
March 1990	1:22	1:23
April 1990	1:35	1:35
May 1990	1:33	1:33
June 1990	1:49	1:39
July 1990	1:41	1:43
August 1990	1:55	1:38
September 1990	1:42	1:46
October 1990	1:38	1:35
November 1990	1:47	1:47
December 1990	1:52	1:44
January 1991	1:50	1:27
February 1991	1:59	1:35
March 1991	1:61	1:41
April 1991	1:49	1:33
May 1991	1:52	1:24
June 1991	1:59	1:27

Source: Demonstration Project's Monthly Progress Reports to HCFA

[a] The average case manager to client ratio was derived by dividing the total hours each case manager spends on case management activities each month by the number of clients assigned to the case managers that month. The average hours spent per case managed client were then converted to a ratio by dividing the number of hours per client by the total hours worked in anaverage month (i.e. 168 hours). In the Model B projects, with a 1:30 case manager to client ratio, each client should receive approximately 5.3 hours of case management per month.

* The sites were allowed a 5% variance above or below the case manager-to-client ratio during the caseload build-up phase due to additions of clients, transitions of cases, additions of staff, etc. For the Model B sites, this variance could range from 28 to 32 clients per case manager and not be out of compliance with the Model B criteria.

the required 5 to 5 1/2 hours per month per client by the end of June. The Wheeling site averaged a case manager-to-client ratio of 1:34.

Case Management Activities

Table WV-5 shows a distribution of case management time among a variety of activities by site location. As can be seen in the table, case managers at the two locations in West Virginia were very different in the allocation of time to case management activities. At both sites, approximately the same percentage of the case managers' time was spent in the initial care planning/service arrangement activities (14.5 percent for Parkersburg and 14.3 percent for Wheeling), case conferences (5.2 percent for Parkersburg and 3.2 percent for Wheeling), caregiver education and training (2 percent for Parkersburg and 1.3 percent for Wheeling), and record keeping (23.6 percent for Parkersburg and 16.6 percent for Wheeling).

However, there were great differences between the allocation of case managers time for certain activities in the two sites. For example, at the Parkersburg site 9.2 percent of case manager's time was spent in an initial client assessment, 21.4 percent of case manager's time was spent in this activity in Wheeling. Similarly, 8.6 percent of case management time was spent in service monitoring/follow-up in Parkersburg versus 16.2 percent in Wheeling. Further, differences were found in public relations activities (2.6 percent for Parkersburg and 0 percent in Wheeling), in administrative meetings (14 percent in Parkersburg versus 15.6 percent in Wheeling), while 8 percent of the Parkersburg case management staff time was spent in travel, only 3 percent of the Wheeling staff time was allocated. Part of this difference in local (vs. out-of-town/rural) may be due to the longer distances the Parkersburg case management staff had to travel to their clients due to the three county area being served and the extension of the catchment area into rural northeastern Ohio.

Demonstration Service Utilization Patterns

During the caseload build-up phase of the demonstration, the number of active clients rose steadily at both of the sites. As shown in Table WV-6, by the first quarter of 1991, the Parkersburg site averaged 89 active clients per month while the Wheeling site averaged 82 active clients per month. By the second quarter of 1991, the Parkersburg site averaged 101 active clients while the Wheeling site averaged 93 clients per month.

After the high of case management-only clients in the first quarter of 1990, there was a steady decline in the Parkersburg site. Of particular interest was the relatively high proportion of client caregivers who were electing to use only the case management services offered by the demonstration. For those clients and their caregivers, there were no direct services being provided

Table WV-5

Medicare Alzheimer's Project: West Virginia
Case Management Activities

Activity	Percent Time Spent in Each Activity[a]	
	Parkersburg	Wheeling
Outreach and Intake	4.9%	0%
Initial Assessment	9.2%	21.4%
Initial Care Planning/Service Arrangement and Costing of Care Plan	14.5%	14.3%
Case Conferences	5.2%	3.2%
Service Monitoring/Follow-up	8.6%	16.2%
Caregiver Education and Training	2.0%	1.3%
Public Relations	2.6%	0%
Administrative/Supervisory Meetings, Reports	4.0%	15.6%
Record Keeping/Data Entry	23.6%	16.6%
Local Travel	8.1%	3.6%
Other	17.3%	7.8%
Total	**100.0%**	**100.0%**

[a] Each case manager completed a time study allocating the total number of hours typically spent during a week in various activities. The Time Study was completed in the Summer of 1990, during the case load build-up phase of the demonstration.

Table WV-6

Medicare Alzheimer's Project: West Virginia
Services Use Patterns by Quarter
(March 1990 through April 1991)

Site and Service Use	1990								1991			
	1st Qtr.[a]		2nd Qtr.		3rd Qtr.		4th Qtr.		1st Qtr.		2nd Qtr.	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Parkersburg												
Average Number Active Treatment Clients per Month	23	100	32	100	47	100	72	100	89	100	101	100
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	6	26	18	56	28	59	45	63	62	70	73	72
Average Number Treatment Clients Receiving Case Management Only	17	74	12	38	14	30	20	28	24	27	18	18
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	NA		2	6	5	11	7	9	3	3	10	10
Wheeling												
Average Number Active Treatment Clients per Month	27	100	36	100	48	100	69	100	82	100	93	100
Average Number Treatment Clients Receiving Both Case Management and Demonstration Services	15	56	13	36	25	52	35	51	47	57	55	60
Average Number Treatment Clients Receiving Case Management Only	12	44	10	28	19	40	26	38	31	38	33	35
Average Number Treatment Clients in Progress (Care Plan Not Yet Implemented)	NA		13	36	4	8	8	11	4	5	5	5

other than case management. The percentages in the Parkersburg site ranged from a high of 74 percent during the second quarter of 1990 to a low of 18 percent in the second quarter of 1991. The percentages at the Wheeling site ranged from a high of 44 percent during the first quarter of 1990 to a low of 28 percent during the second quarter of 1990, although the percentage of case managed-only clients remained very consistent across all six quarters of the enrollment period.

The case managers have identified several factors that impact service utilization patterns. For instance, some of the clients are newly diagnosed and do not, as yet, require additional services. In other cases, there is a discrepancy between what the client/caregiver think they need and what the case manager and/or the Demonstration have to offer; for example, when the case manager may feel that adult day care services would be the best service (or in locations where a variety of service options may not be available, the ONLY service) for the client but the caregiver is not willing to be separated from the client (or vice versa) or the caregiver is unable to get the client to the program (or even be able to have the client ready to go when the program can provide transportation). Thus,.the effort required of the caregiver to get the client "ready" for the services may outweigh the potential benefits. Finally, reluctance to accept services has also impacted the utilization of services. For example, some families are reluctant to accept services due to pride or due to the stigma associated with Alzheimer's disease or the client or caregiver is afraid to have "strangers" in their home.

DESCRIPTIVE SUMMARIES OF THE PROJECTS BY MODEL

Figure 6-1 provides a summary of the Model A projects on key characteristics including: sponsorship, catchment area, program staffing, service environment, program census, compliance with the case management model, case management activities, and demonstration service utilization trends. Figure 6-2 summarizes the Model B projects on the same dimensions.

Figure 6-1
Medicare Alzheimer's Disease Demonstration
Descriptive Summary of Model A Projects

Characteristic and Site	Illinois	New York	Oregon	Tennessee
Sponsorship	The MAP project is sponsored by the Carle Clinic of Urbana-Champaign. Carle Clinic, one of the largest private physician group practices in the country, is affiliated with Carle Foundation. Together, the Clinic and Foundation own and operate a full range of vertically integrated health care services.	Three agencies sponsor the MAP project in Rochester, New York. The Monroe County Long Term Care Program (ACCESS), the Visiting Nurse Service of Rochester, and the Monroe County Health Department. ACCESS is the lead agency.	The MAP project in Portland is sponsored by Good Samaritan Hospital and Medical Center, a major medical center in the Pacific Northwest.	The Alzheimer's Consortium, which sponsors the MAP project, is comprised of 27 health and social services providers. Based on its previous experience in grantsmanship and its experience with the target population, the Northeast Community Mental Health Center was chosen as the lead agency.
Catchment Area	The demonstration operates five locations in East-Central Illinois, including Champaign-Urbana, Bloomington, Danville, Decatur, and Peoria. The catchment area covers 20 counties in Central Illinois.	The catchment area includes all of Monroe County (including the city of Rochester) as well as four rural counties surrounding Rochester, all situated in upstate New York.	The catchment area encompasses both urban and rural areas and includes all of Multnomah, Washington and Clackamas counties as well as portions of Columbia county.	The catchment area is the Memphis Delta Planning and Service Area in the southwest Tennessee, encompassing a large urban county (Shelby) and three rural counties (Lauderdale, Tipton and Fayette).
Program Staffing (April 30, 1991)	Total Staff: 15.3 FTE Administrative/Finance 3.65 Outreach/Intake 1.90 Case Management 2.50 Education/Training 1.50 Research Asst/Case Aide 1.65 Support Staff 3.85 Other .25	Total Staff: 22.55 FTE Administrative/Finance 3.10 Outreach/Intake 12.30 Case Management 2.50 Education/Training 0 Research Asst/Case Aid 1.95 Support Staff 2.70	Total Staff: 15.9 FTE Administrative/Finance 2.40 Outreach/Intake 4.10 Case Management 3.30 Education/Training .20 Research Asst/Case Aide 2.20 Support Staff 3.70	Total Staff: 12.5 FTE Administrative/Finance 1.55 Outreach/Intake 3.25 Case Management 3.05 Education/Training .65 Research Asst/Case Aide 2.00 Support Staff 2.00
Service Environment	Community spokespersons rated the catchment area as having a fair long term care system. Services are limited and accessibility uneven in the 20 county catchment area.	Community spokespersons rated Monroe County as having a well developed long term care system services in the rural counties are not as well developed.	Community spokespersons rated the long term care system as well developed. Relative to the other demonstration sites, the Portland area offered a much broader range of assisted/supported housing.	Community service providers rated the urban long term care system (Shelby County) as well developed. The three rural counties were rated as having a fair long term care system.
Demonstration Service Provision	Carle Clinic is the primary provider of demonstration services. In addition, contracts at the 5 sites range from 15 to 22 service providers. In total, there are 77 contracted service providers.	Two of the MAP sponsors, the Visiting Nurse Services and the Monroe County Health Department provided the majority of the demonstration services. In addition, ACCESS had service contracts with 53 agencies.	The sponsoring agency provided two demonstration services: (1) companion services and (2) caregiver education and training. All other direct services were contracted out to 22 service provider agencies.	Only four of the 17 consortium members provided services to clients. The majority of the direct services were provided under contract with 6 non-consortium member agencies.
Program Census (April 30, 1991)	284 Treatment Clients	263 Treatment Clients	303 Treatment Clients	301 Treatment Clients
Compliance with the Case Management Model (1:100)	During the first 14 months of the project, each case manager usually had at least 10 fewer clients than specified in the Model. However, compliance with the case manager-to-client ratio was achieved by enrollment end but case managers averaged slightly more clients than ideal by the June, 1991.	For the first 14 months of caseload build-up, the case manager-to-client ratio fluctuated substantially and was usually well below the number of clients specified in the model. The project reached compliance by the end of enrollment.	During the first year of the project, for a majority of months, the case managers had at least 20 fewer clients than specified in the model. At the end of the caseload build-up phase, the project was in compliance with the model.	It took nine months for the project to attain compliance with the case management model. Then, in Oct. 1990, the ratio began to fluctuate. After May 1991, each case manager had slightly more cases than specified for Model A sites.
Case Management Activities	Case managers were spending the largest proportions of their time in the following activities: initial care planning/service arrangement (24%) and initial assessment, service monitoring/follow-up, and local travel (each 20%). The Illinois site was unique due to case managers spending about half their time in caregiver education/training and case aides performing many service coordination functions.	The two activities which required the largest proportion of the case managers' time were: service monitoring/follow-up (28%) and initial assessment (19%).	Three activities required the largest proportions of the case managers' time: service monitoring/follow-up (29%); administrative/ supervisory meetings (16%) and initial care planning (15%).	The case managers spent the largest proportion of their time in two activities: service monitoring/follow-up (41%) and initial assessment (18%).
Demonstration Service Utilization Trends (2nd Qtr. 1991)	The proportion of clients using only the case management services of the demonstration decreased over time, from a high of 37% during the 1st quarter 1991 to a low 12% by the end of enrollment.	The proportion of clients using only the case management services of the demonstration increased during the first five quarters of the project, from 8% to 35%, and then declined to 32% by the end of enrollment.	Compared to the other sites, a relatively small proportion of the clients were using only the case management services, ranging from 10-22%, declined to 11% by the end of enrollment.	The proportion of clients using only the case management services of the demonstration increased over time, from 26% to 41% by the end of enrollment.

Medicare Alzheimer's Disease Demonstration
Descriptive Summary of Model B Projects

Characteristic and Site	Florida	Minnesota	Ohio	West Virginia
Sponsorship	The Miami Jewish Home and Hospital for the Aged (MJHHA) sponsors the MAP project. MJHHA is a private nonprofit LTC facility providing community-based social and health services as well as institutional care.	The Minnesota Alzheimer's Consortium is comprised of four health and social service organizations: Wilder Foundation (the lead agency); Metro-Minneapolis/St. Paul Chapter of the Alzheimer's Association, Ebenezer Society, Miller-Dwan Medical Center.	The MAP project is a consortium of five Cincinnati area health and social service providers. Cincinnati Area Senior Services (the lead agency), Senior Citizens of Northern Kentucky, United Home Care, Greater Cincinnati Chapter of ADRDA and the University of Cincinnati Medical Science Center.	Two agencies sponsor the MAP demonstration in West Virginia, the Wood County Senior Citizens Association in Parkersburg and the Family Service - Upper Ohio Valley in Wheeling
Catchment Area	The project serves two counties in the greater Miami area. Dade County and parts of southern Broward County.	The program serves 3 distinct catchment areas: Greater St. Paul catchment area (including Ramsey, Dakota, and Washington County), Greater Minneapolis Catchment area (Hennepin County), and Duluth and the surrounding rural area (St. Louis County).	The catchment area includes all of Hamilton County in Ohio, and Kenton, Campbell, and Boone Counties in Northern Kentucky which encompasses the central metropolitan portion of the greater Cincinnati region.	The project includes two distinct catchment areas: Wood, Pleasants, Wirt, Ritchie, Jackson and Tyler counties in western West Virginia served by the Parkersburg site and Ohio, Wetzel, Marshall, and Brooke counties in the panhandle of northwestern West Virginia served by the Wheeling site.
Program Staffing (April 31, 1991)	Total Staff: 23.8 FTE Administrative/Finance 3.95 Outreach/Intake 1.60 Case Management 13.30 Education/Training .75 Research Asst 0 Support Staff 4.20	Total Staff: 26.6 FTE Administrative/Finance 3.13 Outreach/Intake 2.42 Case Management 14.84 Education/Training .85 Research Asst .28 Support Staff 5.08	Total Staff: 20 FTE Administrative/Finance 4.00 Outreach/Intake 2.50 Case Management 10.00 Education/Training .5 Research Asst 0 Support Staff 3.00	Total Staff: 16.1 FTE Administrative/Finance 3.93 Outreach/Intake 2.76 Case Management 6.03 Education/Training .17 Research Asst 0 Support Staff 2.26 Gerontological RN .95
Service Environment	Community spokespersons rated the long term care service system was well developed. However, if the individual is on Medicaid, the services are somewhat more limited in terms of accessibility, availability, and quality in both counties.	The two urban catchment areas (greater Minneapolis and greater St. Paul) were rated by service providers as having well developed long term care systems. The rural county was rated as having a fair long term care system.	Spokespersons from the service provider community reported that the catchment area had a well developed long term care system. On the other hand, the system was reportedly fragmented and difficult to access, especially for non-Medicaid individuals.	Community spokespersons rated the long term care systems in both catchment areas as fair. However, it was also reported that access to services in the rural areas was a problem and, in general, the need for health and social services outweighs their current availability.
Demonstration Service Provision	MJHHA is the primary provider of direct services for the project. In addition, MAP contracts with 40 different providers, often for multiple services.	In each of the catchment areas, the Consortium's sponsoring agency (Wilder, Ebenezer, and Miller-Dwan) was the primary and preferred provider of services. There were also a large number (157) of contracted providers, who, in many cases, provided services to only one or two clients per provider (e.g. day care).	With the exception of home care, the majority of the services offered under the demonstration are provided by one of the consortium members. There were 47 contracted service providers, and 28 of these were home care contractors.	The two host agencies are the primary service providers for demonstration services. In addition, Wood County Senior Citizens Association had 16 service provider contracts, while the Family Service had 18 service provider contracts.
Program Census (April 31, 1991)	371 Treatment Clients	412 Treatment Clients	306 Treatment Clients	187 Treatment Clients
Compliance with the Case Management Model (1:30)	Throughout the caseload build-up phase, the case managers consistently managed more clients than specified under Model B.	During the first year of the project, at each of the three locations, case managers had fewer clients than specified by the model. By February 1991, the case manager-to-client ratio was in compliance with the model.	During the first 8 months of the project, the case manager-to-client ratios were within an acceptable range for the 1:30 model. After that period, there was slightly more fluctuation with case managers having more clients than specified in the model.	The Parkersburg site case managers consistently managed more clients than the model specified during enrollment. The Wheeling site case managers managed more clients for most of the enrollment period and then attained case manager-to-client ratio by the end of enrollment.
Case Management Activities	The case managers spent the largest proportion of their time on two activities: service monitoring/follow-up (23%) and record keeping/data entry (17%).	At each of the three locations, the case managers spent similar proportions of their time on various activities. The two activities that required the most time were: initial care planning (22.4%) and service monitoring and follow-up (22.0%).	The two activities that required the greatest proportion of the case managers' time were: service monitoring (36%) and initial care planning (15%).	The case managers at the two sites differed somewhat. In Parkersburg case managers spent the most time in: record keeping/data entry (23.6%) and initial care planning /service arrangement (14.5%). In Wheeling: initial assessment (21.4%) and record keeping/data entry (16.6%).
Demonstration Service Utilization Trends (2nd Qtr. 1991)	Clients using only case management fluctuated from a low of 9% to a high of 21% and declined to 10% by the end of enrollment.	Clients using only case management ranged from 20-45% at all 3 sites but declined to approximately 20% by the end of enrollment. The remainder of the clients were utilizing direct health related services as well as case management.	Clients using only case management ranged from 22-30% and declined to 26% by the end of enrollment.	During the early months of the project, fairly large numbers of clients were using only case management services at both sites. By the end of enrollment, clients using only case management declined from 74% to 18% in Parkersburg and from 44% to 35% in Wheeling.

Chapter Seven

PRELIMINARY FINDINGS: CLIENT AND CAREGIVER CHARACTERISTICS

One initial focus in describing the characteristics of the demonstration program participants and their caregivers is to assess the similarity between the samples assigned to the treatment and control groups. The primary reason for conducting a random assignment of applicants into these two groups was to assure observed and unobserved comparability between these groups at enrollment into the demonstration. The absence of systematic differences at baseline provides greater confidence in interpreting, as treatment effects, any systematic differences found at later measurement points . In the following pages, we have provided a number of tables that profile the baseline characteristics of the samples. As will be shown, randomization has achieved comparable groups within each model in virtually every measure tested. There is also a high level of comparability between the two models as well.

All tables have been organized to compare treatment and controls within each model (i.e., Model A and Model B as described in Chapter 2). The first three sections of this chapter have been organized to array the baseline characteristics of the clients and caregivers. There are also two sections concerning measures of program effects. These were collected during a follow-up interview six months after baseline. One section provides data on caregiver stress, burden, and depression. A second section describes caregiver satisfaction with case management and the other services covered by the demonstration program's benefits. The reasons for non-use of these services is also described. Both of these sets of data should be interpreted as preliminary as outcomes may be affected by a range of client and caregiver attributes which have not yet been controlled in these analyses. Additionally, all post-baseline caregiver measures are subject to change, as the population of primary caregivers changes overtime. In other words, if a caregiver change occurs, our procedures collect baseline data on the "new" caregiver and track them forward at 6-month intervals.

CLIENT DIAGNOSES, DEMOGRAPHIC, AND SOCIO-ECONOMIC CHARACTERISTICS

A broad range of cognitive disorders have been used to define the population eligible for this demonstration. The principle requirements were that the condition be irreversible and organic in nature. By far the most prevalent diagnosis among participants in this demonstration is that of Alzheimer's disease, accounting for two-thirds to three-fourths of the sample. As shown in Table 7-1, this is followed by vascular dementia, unspecified dementia, and dementia resulting from degenerative conditions (e.g., Pick's, Parkinson's and Huntington's diseases). There are only minor differences within and between models on the distribution of these diagnoses.[1]

As seen in Tables 7-3 and 7-4 the study sample is predominantly female (about 60 percent) and white (88 percent). Differences between the models (but not the treatment and control groups within models) occur in the proportions black and other (i.e., Hispanic). This is a function largely of the regional location of the programs. Miami's relatively large Hispanic enrollment is the source of "Other" cases in Model B; "Blacks" come largely from Cincinnati. The relatively higher proportion of "Blacks" in Model A is largely a function of Memphis. In general, the demonstration has not attracted a proportionate representation of minorities.

There are no appreciable differences in educational attainment between the models or treatment and control groups, (Table 7-5). Less than one-third of the sample has had some college or more education. Almost an equal proportion have high school or equivalent degrees. The balance (>40 percent) have some high school or less education.

Consistent with education levels is the distribution of income (Table 7-6). More than half the sample have incomes of less than $15,000. About one-fifth have incomes of $25,000 or more. There are no significant differences between models or treatment groups.

Health insurance coverage (Table 7-7) again shows little difference within models, but there are regional (and hence model) differences in the proportions eligible for Medicaid or VA benefits, participating in HMOs, and with Medigap supplemental coverage or retirement health plans. These factors will have to be controlled in any cross-site comparisons.

Living arrangements and type of residence (Tables 7-8 and 7-9 respectively) again reveal no differences within models at baseline. Persons living with a spouse is the most common group at baseline, but substantial numbers live alone or with relatives. Consistent with this, the vast majority of clients live in homes, condominiums, or apartments. Less than 10 percent live in congregate housing or assisted living facilities.

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[1] One explanation for the diagnostic similarity among the sites is the similarity in referral source for applicants. The source of referral into the demonstration is a point of interest to the future administration of any expansion or extension of the case management and Medicare benefit program. The figures shown in Table 7-2 show the referral sources for the developmental phase of the demonstration program, one which featured the 50 percent likelihood of assignment to a control group. It is possible that the relative contribution of these sources would vary in a national program, or under conditions without random assignment. Nevertheless, it is of interest to note that "self," "family referral", and "friends" are the predominant referral sources. Together these account for just over 40 percent of the referrals. Physicians, in spite of their centrality to the family in terms of diagnosis and on-going care, accounted for between only 6 and 11 percent of the referrals. Other health and social service professionals, and community service agencies were somewhat more predominant. Community support groups accounted for about 5 percent of the referrals.

Persons could not be nursing home residents at enrollment. The treatment and control groups begin to diverge, but only slightly from each other at the 6-month follow-up. Both groups show decreases in the proportion living alone or with spouses and increases among those in nursing homes or assisted living. Table 7-10 provides more detail on the sample between study baseline and April 30, 1992. During that interval, about 28 percent of the sample entered a nursing home. Throughout this period, the treatment group, on average, is in the program about 20-30 days longer than the control group before nursing home admission--a possible positive program effect. Treatment group cases, on average, also have 20-40 fewer days in the nursing home before death, another possible program effect. Almost three-quarters of those admitted to nursing home in both groups are still nursing home residents. We urge caution in drawing conclusions from these initial changes and comparisons between models since no adjustments have been made for severity or support systems.

CLIENT PHYSICAL AND COGNITIVE FUNCTIONING

The average age of the study population is almost 79. This is a very impaired group, averaging over 5 limitations in 10 ADL (e.g., walking, transfers, grooming, bathing, eating, toileting) and more than 7 limitations in 8 IADL (e.g., meal preparation, shopping, money management, housework). Table 7-11 shows in summary measures of the physical and cognitive functioning of the sample at study baseline and among the sample remaining after six months. Sample subjects in both models and treatment groups, at both baseline and six-months have essentially identical mean scores in a summation of some or maximum assistance needs for ADL and IADL. Tables 7-12 and 7-13 provide detailed breakouts of the individual functional ability items, distinguishing whether physical or cognitive limitations are the reason for those with some or maximum need. Table 7-14 further refines this listing as it reports only those with maximum needs for ADL assistance.

The BRDRS and the MMSE were used to assess cognitive functioning. The scored results are shown in Table 7-11. Within models there are no differences between treatment and control groups. Scores on both scales indicate that the average client has a mild to moderate level of dementia.

Two additional indicators of functional impairment have been compiled. The first of these profiles patient behavioral problems (Table 7-15). The items in this list do not combine into a validated scale, but they do show comparability between the treatment groups--both at baseline and after six months. The samples report an average of seven to eight problems. The most pervasive problems are "forgetting the current day" and "misplacing things," and "asking repetitive questions." Most of the other problems are reported for half or fewer of the clients. Being a "danger to self or others" is reported for about 10 to 20 percent. There is no marked change in these proportions between baseline and six months. Model B cases reported slightly more problems than those in Model A.

Consistent with these reported problems, and the moderate level of dementia in these samples, about 60 percent of the caregivers report that the clients require "round the clock" supervision. Only about one-fourth are described as needing minimal supervision(Table 7-16).

CAREGIVER CHARACTERISTICS

Common to the elderly population, spouses and female children predominate as the primary caregivers for the demonstration's dementia victims (Table 7-17). Through the first six months after enrollment into the demonstration about 4 to 6 percent of the caregivers changed (Table 7-18). This pattern was consistent across treatment and control groups. Tables 7-19 through 7-22 report the demographic and economic resources of the initial caregivers. There are no meaningful differences in the distribution of any of these attributes between the treatment and control groups in either Model A or B. The primary caregivers, with an average age of 74, are but a few years younger than the person they are helping. More than half are married, usually being the spouse of the victim; but a substantial number are single because of widowhood, divorce, or separation. As a group, caregivers have somewhat more education than those under their care. More than half have at least some college education. Fewer than one-fifth do not have high school degrees. Consistent with their age, about 70 percent of the sample is not working. Among those who are working, the average number of hours of employment per week is 35. Reported incomes of this group suggest that about one-quarter receive less that $15,000 annually while one-third receive under $20,000. The balance is distributed across the income range. Almost one-in-five have incomes of $50,000 or more. Perhaps reflective of the low to moderate income levels of the caregivers, only about a third of the non-spouses regularly contribute to the "care" of the patient (Table 7-23A). Among those contributing the average monthly payment ranges between $290 and $370 at enrollment (Table 7-23B). These generally increased in all groups over six months following enrollment.

From the standpoint of functional ability (Table 7-24), a substantial proportion of the primary caregivers have difficulty performing such basic tasks as housework, shopping, preparing meals, or doing laundry. A number also have ADL limitations, too, particularly getting out of bed or chairs. Consistent with these attributes about 25 percent of the primary caregivers report their health as "fair" or "poor." Less than a third report "excellent" health. Again, there are no meaningful differences among the study samples on these attributes (Table 7-25).

CAREGIVER STRESS, BURDEN, DEPRESSION, AND EMPLOYMENT STATUS

Caregiver stress and burden can come from a variety of sources. Among these are the type of care provided and the hours of care. As seen in Table 7-26, the average dementia victim was receiving between 100 and 115 hours of informal care per week at the time of enrollment into the demonstration. This is the equivalent of almost 16 hours daily. Primary caregivers, on average, claim to be responsible for about 80 percent of this care. Caregiving hours declined for both treatment and control groups among those surviving through the first six months of follow-up. During both periods there are no statistically significant differences between treatment and controls. There are minor differences between models, however.

The level of caregiving and the hours involved appear to have produced, on average, a moderate level of "stress and burden" for the primary caregiver. There is no statistically significant change, on average, in this level of clinical classification after the 6-month follow-up.[1]

Clinical depression has been used as another indicator of effects from caregiving. As seen in Table 7-26, the study population is, on average, just below a level which would define probable depression. While there is no difference between the samples at baseline or after the 6-month follow-up, it should be noted that almost half the primary caregivers are above the threshold value of 5.0 on the Geriatric Depression Scale.[2]

A third indicator used to assess the adverse effects of being a caregiver is that of employment status. Table 7-29 shows that this impact has been substantial. Between 12 and 16 percent had to leave their jobs, and up to 25 percent had to work fewer hours.

CLIENT/CAREGIVER SERVICE USE AND SATISFACTION

To obtain more understanding of service utilization among clients and their caregivers, a series of questions were asked about six of the potentially most needed/beneficial services reimbursed under the demonstration: adult day care, respite care, personal care services, homemaker chore services, companion service, and case management services. For each service we obtained reasons for non-use of services (for non-utilizers of the service) and satisfaction with the service (for service utilizers). These data were compiled for the first time at the 6-month follow-up. They are not available for enrollment baseline.

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[1] Table 7-27A and Table 7-27B provides a description of the distribution of reported problems on each item in the Zarit Stress and Burden Scale.

[2] Table 7-28 provides a description of the distribution of reported problems on each item in the scale.

Preliminary to assessing service use and satisfaction, we also collected information on participation in support groups (Table 7-30) and education and training programs (Table 7-31 and 7-32). Support group participation is higher among those in the treatment group as is the proportion who have received some education on dementia and their roles as caregivers. However, in each case, the proportion participating in these programs is under a third (and usually under 20 percent) of the respondents.

Adult Day Care

There were large differences in the use of adult day care by model and by groups (Table 7-33a). Forty-two percent of the Model B treatment clients were using adult day care compared to 25 percent of the Model A treatment clients. In both Models the proportion of control group members using this service was about half the treatment group level. However, it is important to note that the proportion of controls (23 percent) utilizing adult day care in the Model B sites was almost as high as the proportion of clients (25 percent) using this service in the Model A treatment group.

Two factors may explain the differences between the two models. First, several of the Model B sites encouraged their clients to use adult day care because the case managers felt it offered the most benefit for the dollars spent. Second, in the Model A sites, day care was used with discretion because the relatively high per diem cost could quickly exhaust a client's monthly service expenditure cap (e.g.; day care twice a week at $35 per day would leave the client with only $60 a month for other services.

Subtle differences in case mix between the two models may also contribute to the use pattern. This is suggested in the reasons for non-use of adult day care. At least one-half of the clients in the Model A sites who did not use adult day care reported that the service was "not needed." Another one-fifth reported the client as "too ill." In contrast, only one-fourth of the Model B non-service using clients reported that day care was not needed, while almost one-third were reported as too ill. In the Model B sites the most frequently cited reasons for non-use of day care was that the client/caregiver did not like or could not adapt to the service. Cost, service quality, and availability were relatively minor influences on non-use in both models.

Among those who use adult day care, satisfaction with the services was relatively high. This was true for both models and persons in the control groups, too. At least 75 percent indicated that they were "very satisfied". Over 94 percent reported that they were satisfied or very satisfied with the service (Table 7-33B and 7-33C).

Out-of-Home Respite Care

This service was very infrequently used in any of the demonstration communities. Fewer than 5 percent of either treatment group or their controls reported using this service during the first six months of the evaluation (Table 7-34). The major reason reported for non-use of respite care was that the service was not needed. Slightly higher proportions of the Model A clients cited this reason than did clients in the Model B sites. Model B cases were more likely than those in Model A to report not using respite care because it was not available (approximately 15 percent vs. 8 percent) or because the client/caregiver could not adapt to out-of-home respite care (12 percent vs. 9 percent).

Satisfaction data have not been reported for respite care because the use was so low.

Personal Care Services

Personal care services were used by fewer than half the cases. Persons in the treatment groups were about 20 percent more likely to be using this service than those in the control groups. Model B clients were about 10 percent more likely to use this service than those in Model A (Table 7-35A). Among those not using this service, the major reasons cited for non-use were that the services were not needed (70 percent or more); not affordable, not available, or the client could not adapt. Awareness of the service was slightly higher among treatment group members, and affordability slightly less a problem.

While more than 90 percent of the users of personal care report being "very satisfied" or "satisfied," it should be noted that only 60 percent were "very satisfied," and that control members as a group were more satisfied than those in either treatment model (Tables 7-35B and 7-35C). For both models and groups the main reasons for dissatisfaction were that the service was not available for as many hours as needed (10-15 percent), and staff were not always on schedule. And, there was a surprisingly lower satisfaction with the "knowledge of the care providers" in Model B compared with Model A cases. Controls did as well as or better than the treatment groups on this dimension.

Homemaker Chore Services

In both models approximately one-third of the treatment group used homemaker chore services compared to approximately one-fourth of the control group (Table 7-36A). For all groups the primary reasons cited for non-use of homemaker chore services was that the service was not needed. Slightly more control group clients than treatment clients, in both models, reported that the services were not affordable.

Overall satisfaction with homemaker/chore services was relatively high for treatment and control groups in both models (Table 7-36B and 7-36C), with about 90 percent being either "very satisfied" or "satisfied". This is a level approximately equal to that of personal care services. Here too, the control group was somewhat more satisfied with punctuality of the providers and their knowledge.

Companion Service

In most communities this service complements the in-home assistance of a homemaker or chore worker, by providing shopping assistance, escort or transportation on other errands, and by offering limited in-home client supervision. Companions were used by one-fifth of the control group caregivers. Use rates were 50 to 100 percent higher among those receiving demonstration services (Table 7-37A). Model A cases more frequently used this service. This may in part be a function of price: companions are relatively less expensive than day care or home care, and may be used as alternatives to these other services when monthly benefits have a lower reimbursement level. Rochester, New York in particular used companions, when possible, as a substitute for homemaker chore services because this avoided the state regulatory requirements of skilled nursing assessments and visits. The reasons for not using companions were generally similar to the other in-home support services: "not needed," "caregiver/client could not adapt or did not like", or it was "unaffordable." More persons expressed an unawareness of this service.

Satisfaction with companion services was at least at levels comparable to those of the other services examined (Tables 7-37A and 7-37B). At least 90 percent reported being either very satisfied or satisfied with the services. Control group cases had the same or higher levels of satisfaction. Punctuality of the providers and the hours services were available appear to be the most common problems experienced among all samples.

Case Management

Case management is the cornerstone of the demonstration. Over 95 percent of all demonstration plan members in Models A and B reported the use of this service. Those not "using" the service generally described it as not being needed. Use rates were substantially lower among those in the control groups (Table 7-38A). This was by design. Each demonstration site was limited in the proportion of cases it could enroll who were receiving "intensive" case management at the time of application. This restriction was used in order to minimize the occurrence of cases who were receiving services that essentially replicated the demonstration's intervention. In most sites this made many Medicaid recipients ineligible for the demonstration, since they were receiving similar levels of case management and more extensive benefits under that program. Most control group cases not using case management were "unaware of its availability" or reported it as "not being needed."

The use of case managers can take many forms. For the current analyses we have tracked this in terms of the frequency of contacts (Table 7-38B). As might be expected, there is some difference between the two demonstration models. Model A, with a planned ratio of 1 case manager to 100 clients, has fewer phone contacts and in-person contacts than the Model B counterpart, with it ratio of 1:30. More frequent case manager initiated contacts appears to stimulate, rather than reduce, caregiver initiated contacts. The Model A plan appears to offer a comparable frequency of contacts to that received by the controls.

Satisfaction with case management is relatively high, especially among those in the Model B program, where almost 75 percent are "very satisfied." Over 95 percent of all case management users report being "very satisfied" or "satisfied" (Table 7-38C).

EFFECTS OF SERVICE CO-PAYMENTS ON USE

A final consideration in comparing the two demonstration models with each other is the extent that the difference in individual capitation levels may have influenced service use. This topic will be covered indepth in subsequent analyses that examine expenditures. For the present, Table 7-39 presents caregiver perceptions of services that they "did not use" solely because of the required co-payments on these services. In general, the co-payment requirement appears to have had a minor effect on the use of services. Fewer than 10 percent of the caregivers in each model report this as a reason for not using one or more services. Among the "non-users," the services most affected are home health/personal care aid, day care, companion, and housekeeping services. There are no practical differences between models.

TABLE 7-1

PATIENT DIAGNOSIS
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Diagnosis[1]	Treatment (N=1438) n	Treatment (N=1438) %	Control (N=1392) n	Control (N=1392) %
Model A				
Alzheimer's Disease [a,b]	1017	71.6	927	67.3
Vascular Dementia	307	21.6	322	23.3
Dementia caused by:				
Degenerative disease[2]	122	8.6	123	8.9
CNS infection	3	0.2	3	0.2
Head trauma	13	0.9	20	1.5
Other dementia	154	10.8	141	10.2

Group & Diagnosis[1]	Treatment (N=1641) n	Treatment (N=1641) %	Control (N=1569) n	Control (N=1569) %
Model B				
Alzheimer's Disease	1215	75.1	1132	73.8
Vascular Dementia	373	23.1	323	21.0
Dementia caused by:				
Degenerative disease[2,A]	102	6.3	111	7.2
CNS infection	5	0.3	2	0.1
Head trauma	12	0.7	16	1.0
Other dementia	155	9.6	164	10.7

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between the two models, using X^2 test of significance

[1] Percentages do not sum to 100 because categories are not mutually exclusive.

[2] Includes diseases such as Pick's, Parkinson's, Huntington's.

TABLE 7-2

SOURCE OF PATIENT REFERRAL TREATMENT & CONTROL GROUPS, BY MODEL

Group & Referral Source	Treatment (N=1419)		Control (N=1377)	
	n	%	n	%
Model A [a]				
Self	356	25.1	333	24.2
Family	206	14.5	193	14.0
Friends	79	5.6	86	6.2
Physician	142	10.0	148	10.7
Other health/social service professional	155	10.9	169	12.3
Hospital	40	2.8	36	2.6
Nursing home (SNF/ICF)	3	0.2	3	0.2
Adult foster care/board & care/residential care or or personal care home	8	0.6	13	1.0
Retirement facility	10	0.7	7	0.6
Home health care agency	66	4.6	68	4.9
Adult day care provider	45	3.2	37	2.7
Other community social service provider	91	6.4	107	7.8
Community support group	72	5.1	62	4.5
Other	146	10.3	115	8.3

Group & Referral Source	Treatment (N=1617)		Control (N=1539)	
	n	%	n	%
Model B				
Self	351	21.6	340	22.0
Family	242	15.0	242	14.4
Friends	101	6.2	118	7.6
Physician	104	6.4	105	6.8
Other health/social service professional	189	11.7	189	12.3
Hospital	69	4.3	65	4.3
Nursing home (SNF/ICF)	16	1.0	7	0.5
Adult foster care/board & care/residential care or or personal care home	15	0.9	12	0.8
Retirement facility	10	0.7	13	0.9
Home health care agency	61	3.8	65	4.2
Adult day care provider	97	6.0	93	6.0
Other community social service provider	163	10.1	151	9.8
Community support group	52	3.2	37	2.4
Other	147	9.1	123	8.0

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between the two models, using X^2 test of significance

[1] Percentages do not sum to 100 because categories are not mutually exclusive.

TABLE 7-3

PATIENT GENDER
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Gender	Treatment (N=1438)		Control (N=1392)	
	n	%	n	%
Model A[b]				
Female	875	60.9	787	56.5
Male	563	39.1	605	43.5

Group & Gender	Treatment (N=1641)		Control (N=1569)	
	n	%	n	%
Model B				
Female	998	60.8	939	59.8
Male	643	39.2	630	40.2

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[b] $p < .05$ between the treatment and control groups, using X^2 test of significance

TABLE 7-4

PATIENT RACE
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Race	Treatment (N=1437)		Control (N=1392)	
	n	%	n	%
Model A[a]				
Black	162	11.3	143	10.3
White	1247	87.2	1230	88.6
Other[1]	21	1.5	14	1.1
Group & Race	**(N=1641)**		**(N=1564)**	
	n	%	n	%
Model B				
Black	83	5.1	94	6.0
White	1461	89.1	359	87.3
Other[1]	95	5.8	103	6.6

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between the two models, using X^2 test of significance

[1] Other category includes American Indian, Asian, Pacific Islander, Filipino, Hispanic, and Other.

TABLE 7-5

PATIENT EDUCATION ATTAINMENT
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Education	Treatment (N=1427)		Control (N=1385)	
	n	%	n	%
Model A				
No formal schooling	24	1.7	31	2.2
Elementary schooling	374	26.2	354	25.6
Some high school	244	17.1	231	16.7
High school or equivalent	369	25.9	405	29.2
Some college	206	14.4	207	15.0
College graduate	140	9.8	93	6.7
Post graduate [a]	70	4.9	64	4.6
Group & Education	(N=1628)		(N=1555)	
	n	%	n	%
Model B				
No formal schooling	29	1.8	17	1.1
Elementary schooling	354	21.8	366	23.6
Some high school	322	19.8	313	20.1
High school or equivalent	463	28.4	455	29.3
Some college	237	14.5	209	13.4
College graduate	143	8.8	114	7.3
Post graduate	80	4.9	81	5.2

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation , 1992

[a] $p < .05$ between the two models, using X^2 test of significance

TABLE 7-6

PATIENT INCOME
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Income	Treatment (N=1384)		Control (N=1347)	
	n	%	n	%
Model A				
$0-9,999	469	33.9	476	35.3
$10,000-14,999	299	21.6	297	22.0
$15,000-19,999	202	14.6	192	14.3
$20,000-24,999	140	10.1	140	10.4
$25,000-29,999	86	6.2	83	6.2
$30,000-34,999	53	3.8	55	4.1
$35,000-39,999	33	2.4	29	2.2
$40,000-44,999	26	1.9	20	1.5
$45,000-49,999	27	1.9	15	1.1
$50,000 and over	50	3.6	40	3.0
Group & Income	(N=1582)		(N=1508)	
Model B	n	%	n	%
$0-9,999	568	35.9	526	34.8
$10,000-14,999	363	22.9	341	22.6
$15,000-19,999	235	14.9	220	14.6
$20,000-24,999	134	8.5	137	9.1
$25,000-29,999	89	5.6	97	6.4
$30,000-34,999	53	3.4	56	3.7
$35,000-39,999	41	2.6	40	2.6
$40,000-44,999	26	1.6	30	2.0
$45,000-49,999	25	1.6	16	1.1
$50,000 and over	48	3.0	47	3.1

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-7

PATIENT HEALTH CARE COVERAGE
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Coverage	Treatment			Control		
	n	%	Total	n	%	Total
Model A[1]						
Medicaid[a]	116	8.1	1426	99	7.2	1381
Health Maintenance Organization[a,b]	270	18.9	1431	248	18.0	1382
Veterans Administration[b]	51	3.6	1427	39	2.8	1381
CHAMPUS	3	0.2	1426	3	0.2	1381
Retirement health plan[a,b]	314	22.0	1423	348	25.2	1377
Medigap supplemental insurance	495	34.6	1429	482	35.0	1377
Other[a]	197	13.9	1415	176	12.8	1366

Group & Coverage[1]	n	%	Total	n	%	Total
Model B						
Medicaid	84	5.2	1621	93	6.0	1553
Health Maintenance Organization[1]	417	25.7	1623	347	22.4	1549
Veterans Administration[1]	50	3.1	1619	30	1.9	1547
CHAMPUS	2	0.1	1617	7	0.4	1551
Retirement health plan	248	15.3	1622	261	16.9	1546
Medigap supplemental insurance	755	46.5	1621	675	43.6	1547
Other	77	4.8	1598	82	5.3	1521

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between the two models, using X^2 test of significance

[b] $p < .05$ between the treatment and control groups, using X^2 test of significance

[1] Percentages do not sum to 100 because categories are not mutually exclusive.

TABLE 7-8

PATIENT LIVING ARRANGEMENT
TREATMENT & CONTROL GROUPS, BY MODEL

	Baseline				6 Month			
Group & Arrangement[1]	Treatment (N=1437)		Control (N=1391)		Treatment (N=1229)		Control (N=1174)	
Model A	n	%	n	%	n	%	n	%
Alone	204	14.2	199	14.3	146	11.9	135	11.5
Household with spouse only	644	44.8	606	43.6	478	38.9	428	36.5
Household with spouse & others	76	5.3	84	6.0	64	5.2	76	6.5
Household with relatives	420	29.2	391	28.1	289	23.5	260	22.1
Household with non-relatives only	39	2.7	39	2.8	69	5.6	74	6.3
In health-related facility	9	0.6	13	0.9	173	14.1	177	15.1
Other	45	3.1	59	4.2	10	0.8	24	2.0
Group & Arrangement[1]	Treatment (N=1637)		Control (N=1561)		Treatment (N=1389)		Control (N=1296)	
Model B	n	%	n	%	n	%	n	%
Alone	214	13.1	205	13.1	136	9.7	111	8.5
Household with spouse only	763	46.6	715	45.8	530	38.2	479	37.0
Household with spouse & others	82	5.0	96	6.1	96	6.9	97	7.5
Household with relatives	467	28.5	446	28.6	315	22.7	269	20.8
Household with non-relatives only	43	2.6	42	2.7	66	4.8	76	5.9
In health-related facility	16	1.0	15	1.0	224	16.1	239	18.4
Other	52	3.2	42	2.7	22	1.6	25	1.9

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[1] Percentages do not sum to 100 because categories are not mutually exclusive.

TABLE 7-9

PATIENT RESIDENCE
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Arrangement	Baseline[a]				6 Month[a]			
	Treatment (N=1436)		Control (N=1391)		Treatment (N=1229)		Control (N=1170)	
Model A	n	%	n	%	n	%	n	%
House	1107	77.1	1109	79.7	791	64.3	762	65.1
Condominium	37	2.6	23	1.7	17	1.4	14	1.2
Apartment	153	10.7	140	10.1	91	7.4	80	6.8
Room: Hotel/house	2	0.1	1	0.1	0	0.0	2	0.2
Mobile home	57	4.0	34	2.4	38	3.1	22	1.9
Senior residential facility	48	3.3	42	3.0	35	2.8	32	2.7
Residential care facility	15	1.0	24	1.7	69	5.6	82	7.0
Nursing Home	0	0.0	0	0.0	177	14.4	167	14.3
Other	17	1.2	18	1.3	11	0.9	9	0.8

Group & Arrangement	Baseline				6 Month			
	Treatment (N=1639)		Control (N=1561)		Treatment (N=1379)		Control (N=1285)	
Model B	n	%	n	%	n	%	n	%
House	1105	67.4	1035	66.3	787	57.0	633	51.6
Condominium	184	11.2	151	9.7	122	8.8	99	7.7
Apartment	179	10.9	216	13.8	117	8.5	140	10.9
Room: Hotel/house	2	0.1	2	0.1	0	0.0	0	0.0
Mobile home	26	1.6	22	1.4	18	1.3	11	0.9
Senior residential facility	75	4.6	73	4.7	54	3.9	44	3.4
Residential care facility	40	2.4	41	2.6	76	5.5	101	7.9
Nursing Home	0	0.0	0	0.0	195	14.1	216	16.8
Other	28	1.8	21	1.4	10	0.7	11	0.9

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between the two models, using X^2 test of significance

TABLE 7-10

NURSING HOME UTILIZATION BETWEEN DATE OF ENTRY AND 4/30/92 BY MODEL AND TREATMENT GROUP

	Model A	Model B
Number Persons in Sample[1]		
Treatment	1378	1557
Control	1328	1495
Percent Admitted to Nursing Home		
Treatment	27.6	28.7
Control	23.8	27.0
Mean Days in Program Before NH Admission		
Treatment	287.0	295.2
Control	274.0	268.0
Mean Days in Nursing Home Before Death		
Treatment	146.2	138.9
Control	165.8	181.2
Percent of NH Admissions Still in NH		
Treatment	76.7	72.2
Control	84.6	77.8

SOURCE: UCSF/Instit. for Health and Aging. HCFA-Alzheimer's Disease Evaluation, 1992

[1] Sample has been adjusted to remove all cases who died or were in nursing homes within 31 days after randomization into the demonstration.

TABLE 7-11

PATIENT AGE AND FUNCTIONAL MEASURES
TREATMENT & CONTROL GROUPS, BY MODEL

	Baseline				6 Month			
Group & Arrangement	Treatment		Control		Treatment		Control	
Model A	n	Mean	n	Mean	n	Mean	n	Mean
Age	1220	78.5	1170	78.6	1224	78.8	1172	79.2
ADL[1]	1187	5.5	1131	5.5	1014	5.4	939	5.4
IADL[1]	1226	7.4	1173	7.4	1031	7.5	973	7.4
BRDRS[2]	1230	7.9	1177	7.8	1083	8.9	1037	8.6
MMSE[3]	1356	14.2	1324	14.3	•	•	•	•
Group & Arrangement								
Model B	n	Mean	n	Mean	n	Mean	n	Mean
Age	1389	78.8	1290	79.4	1384	79.2	1291	79.7
ADL[1]	1350	5.7	1247	5.6	1121	5.9	1024	5.8
IADL[1]	1394	7.5	1296	7.5	1144	7.6	1038	7.5
BRDRS[2]	1393	8.4	1297	8.2	1200	9.2	1108	9.2
MMSE[3]	1528	13.4	1446	13.3	•	•	•	•

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

•Test not completed at 6-month follow-up. The construction of each scale includes only persons who answered all items in the scale.

[1] ADL and IADL scores are based on persons needing some or maximum assistance.

[2] BRDRS. Values can range from 1 to 17. Higher scores are indicative of greaterimpairment. Five or more mistakes is indicative of some cognitive impairment. Scores between 7 and 12 are indicative of mild to moderate impairment.

[3] MMSE. Values can range from 1 to 30. Lower scores are indicative of greater impairment. A score of 12 or under indicates moderate to severe impairment, 13 to 23 indicates moderate to mild impairment.

TABLE 7-12

LIMITATIONS IN ACTIVITIES OF DAILY LIVING AND REASON FOR ASSISTANCE MODEL A: TREATMENT & CONTROL GROUPS

Group by ADL & Reason	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Model A												
Transportation	1352			1289			1006			928		
cognitive		587	43.4		592	45.9		467	46.4		418	45.0
physical		91	6.7		86	6.7		62	6.2		64	6.9
cognitive/physical		674	49.9		611	47.4		477	47.4		446	48.1
Walking [c]	528			475			273			285		
cognitive		52	9.8		47	9.9		22	8.0		29	10.2
physical		134	25.4		112	23.6		39	14.3		52	18.2
cognitive/physical		342	64.8		316	66.5		212	77.7		204	71.6
Wheeling [c]	231			237			214			188		
cognitive		23	10.0		19	8.0		18	8.4		17	9.0
physical		48	20.8		58	24.5		35	16.4		44	23.4
cognitive/physical		160	69.2		160	67.5		161	75.2		127	67.6
Transfers (bed/chair) [c]	484			444			301			307		
cognitive		55	11.4		49	11.1		31	10.3		39	12.7
physical		121	25.0		112	25.2		46	15.3		64	20.8
cognitive/physical		308	63.6		283	63.7		224	74.4		204	66.5
Grooming [a]	1027			989			728			696		
cognitive		470	45.8		456	46.1		337	46.3		313	45.0
physical		110	10.7		99	10.0		49	6.7		57	8.2
cognitive/physical		447	43.5		434	43.9		342	47.0		326	46.8
Bathing	1045			993			763			710		
cognitive		466	44.6		428	43.1		327	42.9		314	44.2
physical		113	10.8		100	10.1		53	6.9		57	8.1
cognitive/physical		466	44.6		465	46.8		383	50.2		339	47.7
Dressing [c]	996			942			689			644		
cognitive		482	48.4		466	49.5		308	44.7		287	44.6
physical		95	9.5		79	8.4		40	5.8		46	7.1
cognitive/physical		419	42.1		397	42.1		341	49.5		311	48.3
Eating [c]	707			661			459			427		
cognitive		290	41.0		261	39.5		180	39.2		150	35.1
physical		118	16.7		107	16.2		33	7.2		55	12.9
cognitive/physical		299	42.3		293	44.3		246	53.6		222	52.0
Toileting	652			593			465			420		
cognitive		254	39.0		211	35.6		185	39.8		138	32.9
physical		84	12.9		71	12.0		24	5.2		36	8.6
cognitive/physical		314	48.1		311	52.4		256	55.0		246	58.5
Bowel/bladder accidents	701			693			532			495		
cognitive		245	35.0		247	35.6		203	38.1		174	35.2
physical		104	14.8		111	16.1		44	8.3		53	10.7
cognitive/physical		352	50.2		335	48.3		285	53.6		268	54.1

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between the two models at baseline, using X^2 test of significance

[c] $p < .05$ between the two models at 6-month follow-up, using X^2 test of significance

TABLE 7-12 CONTINUED

LIMITATIONS IN ACTIVITIES OF DAILY LIVING AND REASON FOR ASSISTANCE
MODEL B: TREATMENT & CONTROL GROUPS

Group by ADL & Reason	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Model B												
Transportation	1513			1429			1088			998		
cognitive		676	44.7		604	42.2		487	44.8		490	49.1
physical		97	6.4		104	7.3		60	5.5		52	5.2
cognitive/physical		740	48.9		721	50.5		541	49.7		456	45.7
Walking	606			611			454			418		
cognitive		76	12.5		74	12.1		80	17.6		80	19.2
physical		146	24.1		158	25.9		86	18.9		98	23.4
cognitive/physical		384	63.4		379	62.0		288	63.5		240	57.4
Wheeling	279			302			249			229		
cognitive		27	9.7		38	12.6		34	13.7		36	15.7
physical		53	19.0		68	22.5		41	16.4		43	18.8
cognitive/physical		199	71.3		196	64.9		174	69.9		150	65.5
Transfers (bed/chair)	551			537			414			369		
cognitive		56	10.2		62	11.5		82	19.8		73	19.8
physical		154	27.9		152	28.3		79	19.1		78	21.1
cognitive/physical		341	61.9		323	60.2		253	61.1		218	59.1
Grooming	1270			1193			887			774		
cognitive		646	50.9		586	49.1		440	49.6		376	48.6
physical		99	7.8		110	9.2		56	6.3		43	5.5
cognitive/physical		525	41.3		497	41.7		391	44.1		355	45.9
Bathing	1261			1175			905			788		
cognitive		560	44.4		515	43.8		410	45.3		370	47.0
physical		110	8.7		112	9.6		62	6.39		56	7.1
cognitive/physical		591	46.9		548	46.6		433	47.8		362	45.9
Dressing	1191			1121			818			744		
cognitive		611	51.3		548	48.9		421	51.5		388	52.1
physical		76	6.4		91	8.1		40	4.9•		49	6.6
cognitive/physical		504	42.3		482	43.0		357	43.6		307	41.3
Eating	805			752			571			515		
cognitive		342	42.5		308	41.0		248	43.4		212	41.2
physical		106	13.2		112	14.9		60	10.5		51	9.9
cognitive/physical		357	44.3		332	44.1		263	46.1		252	48.9
Toileting	750			743			546			512		
cognitive		302	40.3		285	38.4		219	40.1		222	43.4
physical		63	8.4		81	10.9		40	7.3		34	6.6
cognitive/physical		385	51.3		377	50.7		287	52.6		256	50.0
Bowel/bladder accidents	848			820			673			590		
cognitive		292	34.4		277	33.8		246	36.6		225	38.1
physical		127	15.0		117	14.2		81	12.0		75	12.7
cognitive/physical		429	50.6		426	52.0		346	51.4		290	49.2

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease, 1992

TABLE 7-13

INSTRUMENTAL ACTIVITIES OF DAILY LIVING LIMITATIONS AND REASON FOR ASSISTANCE
MODEL A: TREATMENT & CONTROL GROUPS

Group by IADL & Reason	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
Model A	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Meal preparation [a,c,d]												
cognitive	1346	763	56.7	1301	737	56.6	972	521	53.6	919	473	51.5
physical		70	5.2		66	5.1		33	3.4		57	6.2
cognitive/physical		513	38.1		498	38.3		418	43.0		389	42.3
Shopping [a,c,d]												
cognitive	1368	688	50.3	1320	674	51.1	1009	503	49.9	940	459	48.8
physical		84	6.1		65	4.9		41	4.1		54	5.7
cognitive/physical		596	43.6		581	44.0		465	46.0		427	45.5
Routine housework [a,c]												
cognitive	1327	596	44.9	1273	57.345.0		974	453	46.5	916	414	45.2
physical		111	8.4		92	7.2		59	6.1		61	6.7
cognitive/physical		620	46.7		608	47.8		462	47.4		441	48.1
Money management [a,c]												
cognitive	1395	1015	72.8	1350	987	73.1	1006	718	71.4	957	669	69.9
physical		29	2.1		34	2.5		18	1.8		20	2.1
cognitive/physical		351	25.1		329	24.4		270	26.8		268	28.1
Laundry [c,d]												
cognitive	1303	675	51.8	1262	668	52.9	973	490	50.4	897	428	47.7
physical		77	5.9		74	5.9		48	4.9		55	6.1
cognitive/physical		551	42.3		520	41.2		435	44.7		414	46.2
Medications [c]												
cognitive	1300	911	70.0	1250	898	71.8	930	626	67.3	876	574	65.6
physical		23	1.8		21	1.7		12	1.3		17	1.9
cognitive/physical		366	28.2		331	26.5		292	31.4		285	32.5
Telephone [a,c,d]												
cognitive	1183	751	63.5	1153	742	64.3	867	521	60.1	823	469	57.0
physical		58	4.9		54	4.7		25	2.9		37	4.5
cognitive/physical		374	31.6		357	31.0		321	37.0		317	38.5
Heavy chores/home maint [a,d]												
cognitive	1379	366	26.5	1325	332	25.0	996	356	35.7	924	314	34.0
physical		133	9.7		107	8.1		65	6.6		74	8.0
cognitive/physical		880	63.8		886	66.9		575	57.7		536	58.0

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation , 1992[a] $p < .05$ between the two models at baseline, using X^2 test of significance

[c] $p < .05$ between the two models at 6-month follow-up, using X^2 test of significance

[d] $p < .05$ between the treatment and control at 6-month follow-up, using X^2 test of significance

TABLE 7-13 CONTINUED
INSTRUMENTAL ACTIVITIES OF DAILY LIVING LIMITATIONS AND REASON FOR ASSISTANCE
MODEL A: TREATMENT & CONTROL GROUPS

Group by IADL & Reason	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
Model B	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Meal preparation												
cognitive	1573	918	58.4	1488	871	58.5	1102	666	60.4	996	594	59.6
physical		55	3.5		66	4.4		34	3.4		40	4.1
cognitive/physical		600	38.1		551	37.1		402	36.5		362	36.3
Shopping												
cognitive	1585	805	50.8	1515	770	50.8	1110	596	53.7	1012	552	54.5
physical		48	3.0		62	4.1		42	3.8		42	4.2
cognitive/physical		732	46.2		683	45.1		472	42.5		418	41.3
Routine housework												
cognitive	1528	677	44.3	1447	649	44.9	1073	537	50.0	973	495	50.9
physical		84	5.5		91	6.2		54	5.1		51	5.2
cognitive/physical		767	50.2		707	48.9		482	44.9		427	43.9
Money management												
cognitive	1612	1233	76.5	1540	1212	78.7	1115	838	75.2	1024	757	73.9
physical		15	0.9		14	0.9		10	0.9		16	1.6
cognitive/physical		364	22.6		314	20.4		267	23.9		251	24.5
Laundry												
cognitive	1526	754	49.4	1456	748	51.4	1080	583	54.0	981	519	52.9
physical		66	4.3		77	5.3		38	3.5		53	5.4
cognitive/physical		706	46.3		631	43.3		459	42.5		409	41.7
Medications												
cognitive	1519	1113	73.3	1454	1109	76.2	1065	752	70.6	961	679	70.7
physical		17	1.1		14	1.0		13	1.2		17	1.8
cognitive/physical		389	25.6		331	22.8		300	28.2		265	27.5
Telephone												
cognitive	1356	906	66.8	1285	889	69.2	991	641	64.7	872	565	64.8
physical		44	3.3		37	2.9		22	2.2		22	2.5
cognitive/physical		406	29.9		359	27.9		328	33.1		285	32.7
Heavy chores/home maint.												
cognitive	1589	437	27.5	1525	452	29.6	1113	382	34.4	1010	356	35.2
physical		130	8.2		138	9.1		65	5.8		72	7.2
cognitive/physical		1022	64.3		935	61.3		666	59.8		582	57.6

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-14

LIMITATIONS IN ACTIVITIES OF DAILY LIVING AND REASON FOR ASSISTANCE FOR PERSONS REQUIRING MAXIMUM HELP MODEL A: TREATMENT & CONTROL GROUPS

Group by ADL & Reason	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Model A												
Transportation ^{c}	283			267			160			142		
cognitive		46	16.2		52	19.5		10	6.3		15	10.6
physical		39	13.8		35	13.1		13	8.1		19	13.4
cognitive/physical		198	70.0		180	67.4		137	85.6		108	76.0
Walking ^{d}	238			222			146			135		
cognitive		20	8.4		15	6.8		8	5.8		11	8.2
physical		56	23.5		44	19.8		14	9.3		25	18.5
cognitive/physical		162	68.1		163	73.4		124	84.9		99	73.3
Wheeling ^{c}	171			161			154			142		
cognitive		17	9.9		13	8.1		11	7.3		13	9.2
physical		28	16.4		26	16.1		15	9.6		23	16.2
cognitive/physical		126	73.7		122	75.8		128	83.1		106	74.6
Transfers (bed/chair) ^{c,d}	206			193			159			150		
cognitive		17	8.3		11	5.7		11	6.9		14	9.3
physical		33	16.0		37	19.2		13	8.2		30	20.0
cognitive/physical		156	75.7		145	75.1		135	84.9		106	70.7
Grooming	529			513			406			394		
cognitive		182	34.4		179	34.9		142	35.0		130	33.0
physical		39	7.4		37	7.2		14	3.4		36	9.1
cognitive/physical		308	58.2		297	57.9		250	61.6		228	57.9
Bathing ^{d}	524			488			428			408		
cognitive		159	30.3		136	27.9		139	32.5		136	33.3
physical		50	9.5		39	8.0		17	4.0		35	8.6
cognitive/physical		315	60.2		313	64.1		272	63.5		237	58.1
Dressing ^{c,d}	445			393			358			345		
cognitive		142	31.9		109	27.7		113	31.6		95	27.5
physical		40	9.0		36	9.2		11	3.0		28	8.2
cognitive/physical		263	59.1		248	63.1		234	65.4		222	64.3
Eating	150			132			130			111		
cognitive		34	22.7		30	22.7		26	20.0		19	17.1
physical		11	7.3		11	8.4		5	3.8		7	6.3
cognitive/physical		105	70.0		91	68.9		99	76.2		85	76.6
Toileting ^{c}	258			247			237			200		
cognitive		59	22.9		58	23.5		61	25.7		42	21.0
physical		23	8.9		28	11.3		9	3.8		13	6.5
cognitive/physical		176	68.2		161	65.2		167	70.5		145	72.5
Bowel/bladder accidents	391			359			318			302		
cognitive		115	29.4		100	27.9		98	30.8		89	29.5
physical		39	10.0		42	11.7		14	4.4		17	5.6
cognitive/physical		237	60.6		217	60.4		206	64.8		196	64.9

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

^{a} $p < .05$ between the two models at baseline, using X^2 test of significance
^{c} $p < .05$ between the two models at 6-month follow-up, using X^2 test of significance
^{d} $p < .05$ between the treatment and control at 6-month follow-up, using X^2 test of significance

TABLE 7-14 CONTINUED
LIMITATIONS IN ACTIVITIES OF DAILY LIVING AND REASON FOR ASSISTANCE FOR PERSONS REQUIRING MAXIMUM HELP
MODEL B: TREATMENT & CONTROL GROUPS

	Baseline						6 Month					
Group by IADL & Reason	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Model B												
Transportation	379			397			260			249		
cognitive		85	22.4		86	21.7		58	22.4		66	26.5
physical		37	9.8		49	12.3		23	8.8		13	5.2
cognitive/physical		257	67.8		262	66.0		179	68.8		170	68.3
Walking	248			252			192			170		
cognitive		23	9.2		23	9.1		19	9.9		22	12.9
physical		53	21.4		50	19.8		24	12.5		27	15.9
cognitive/physical		172	69.4		179	71.1		149	77.6		121	71.2
Wheeling	219			241			169			161		
cognitive		22	10.0		33	13.7		27	16.0		22	13.7
physical		30	13.7		39	16.2		15	8.9		22	13.7
cognitive/physical		167	76.3		169	70.1		127	75.1		117	72.6
Transfers (bed/chair)	232			143			181			157		
cognitive		19	8.2		21	8.6		22	12.2		22	14.0
physical		41	17.7		44	18.1		14	7.7		18	11.5
cognitive/physical		172	74.1		178	73.3		145	80.1		117	74.5
Grooming	670			624			445			387		
cognitive		259	38.6		231	37.0		168	37.8		152	39.3
physical		44	6.6		39	6.3		21	4.7		15	3.9
cognitive/physical		367	54.8		354	56.7		256	57.5		220	56.8
Bathing	670			626			513			455		
cognitive		220	32.8		204	32.6		187	36.5		172	37.8
physical		44	6.6		47	7.5		20	3.9		23	5.1
cognitive/physical		406	60.6		375	59.9		306	59.6		260	57.1
Dressing	534			526			381			342		
cognitive		177	33.1		176	33.5		128	33.6		124	36.2
physical		27	5.1		35	6.6		15	3.9		18	5.3
cognitive/physical		330	61.8		315	59.9		238	62.5		200	58.5
Eating	183			195			173			147		
cognitive		43	23.5		46	23.6		46	26.6		31	21.1
physical		13	7.1		13	6.7		9	5.2		5	3.4
cognitive/physical		127	69.4		136	69.7		118	68.2		111	75.5
Toileting	328			329			276			249		
cognitive		84	25.6		83	25.3		80	29.0		75	30.1
physical		26	7.9		31	9.4		21	7.6		16	6.4
cognitive/physical		218	66.5		215	65.3		175	63.4		158	63.5
Bowel/bladder accidents	506			472			351			318		
cognitive		153	30.2		137	29.0		102	29.1		112	35.2
physical		58	11.5		52	11.0		25	7.1		23	7.3
cognitive/physical		295	58.3		283	60.0		224	63.8		183	57.5

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-15

PATIENT BEHAVIORAL PROBLEMS
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Problem	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
Model A	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Asks repetitive questions [c]	1436	928	64.6	1390	944	67.9	1032	572	55.4	978	558	57.1
Suspicious or accusative [a,c]	1435	677	47.2	1390	714	51.4	1031	408	39.6	977	400	40.9
Trouble recognizing people [a,c]	1436	783	54.5	1391	773	55.6	1032	598	57.9	978	581	59.4
Forgets the current day [d]	1435	1298	90.4	1391	1261	90.6	1032	963	93.3	978	876	89.6
Embarrassing to caregiver [a,c]	1432	535	37.4	1386	525	37.9	1029	307	29.8	976	312	32.0
Wakes caregiver at night [a,c]	1435	639	44.5	1390	589	42.4	1030	391	38.0	976	373	38.2
Constantly restless [c]	1434	666	46.4	1390	655	47.1	1031	419	40.6	979	394	40.2
Constantly talkative [c]	1433	402	28.1	1391	404	29.0	1031	278	27.3	978	225	23.0
Relives past situations [a,c]	1433	667	46.6	1391	631	45.4	1032	426	41.3	979	383	39.1
Hallucinations/illusions [a,c]	1431	595	41.6	1390	573	41.2	1031	401	38.9	979	376	38.4
Unreasonable anger [a,c]	1433	627	43.7	1388	598	43.1	1032	380	36.8	979	367	37.5
Combative [a,c]	1431	336	23.5	1385	316	22.8	1031	229	22.2	978	204	20.9
Wanders/gets lost [a,c]	1436	372	25.9	1391	342	24.6	1032	218	21.1	979	204	20.8
Hides things (money, jewelry) [a]	1435	621	43.3	1391	663	47.7	1032	465	45.1	979	462	47.2
Loses or misplaces things [c]	1436	1070	74.5	1391	1049	75.4	1032	657	63.7	978	651	66.6
Leaves tasks uncompleted [c]	1436	743	51.7	1391	738	53.1	1032	489	47.4	978	496	50.7
Destroys property	1436	160	11.1	1390	145	10.4	1032	113	10.9	979	109	11.1
Potential danger to others [a]	1436	126	8.8	1391	122	8.8	1031	99	9.6	978	81	8.3
Potential danger to self [c]	1436	257	17.9	1391	262	18.8	1030	156	15.1	978	129	13.2
Mean # of Problems	7.4	(SD=3.6)		7.3	(SD=3.6)		7.3	(SD=3.0)		7.3	(SD=4.0)	
Model B	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Asks repetitive questions	1636	1121	68.5	1563	1066	68.2	1146	703	61.3	1047	660	63.0
Suspicious or accusative	1634	852	52.1	1561	817	52.3	1146	561	48.9	1047	503	48.0
Trouble recognizing people	1636	985	60.2	1562	935	59.9	1144	715	62.5	1047	641	61.2
Forgets the current day	1635	1549	94.7	1561	1473	94.4	1145	1054	92.1	1047	951	90.8
Embarrassing to caregiver	1635	712	43.5	1561	618	39.6	1145	477	41.7	1045	379	36.3
Wakes caregiver at night	1634	793	48.5	1562	760	48.7	1145	513	44.8	1047	474	45.3
Constantly restless	1635	730	44.6	1563	719	46.0	1146	549	47.9	1047	482	46.0
Constantly talkative	1632	455	27.9	1560	397	25.4	1146	330	28.8	1046	318	30.4
Relives past situations	1633	814	49.8	1563	765	48.9	1146	508	44.3	1045	446	42.7
Hallucinations/illusions	1636	740	45.2	1561	675	43.2	1146	523	45.6	1045	448	42.9
Unreasonable anger	1635	793	48.5	1559	738	47.3	1145	550	48.0	1045	500	47.9
Combative	1633	457	28.0	1560	424	27.2	1146	332	29.0	1045	289	27.7
Wanders/gets lost	1636	465	28.4	1562	430	27.5	1145	320	27.9	1046	296	28.3
Hides things (money, jewelry)	1635	798	48.8	1560	749	48.0	1144	547	47.8	1046	507	48.5
Loses or misplaces things	1636	1237	75.6	1562	1158	74.1	1145	796	69.5	1046	709	67.8
Leaves tasks uncompleted	1635	908	55.5	1558	843	54.1	1145	524	45.8	1046	454	43.4
Destroys property	1635	191	11.7	1561	186	11.9	1145	140	12.2	1046	139	13.3
Potential danger to others	1635	182	11.1	1562	164	10.5	1145	121	10.6	1045	103	9.9
Potential danger to self	1636	322	19.7	1561	326	20.9	1145	228	19.9	1044	194	18.6
Mean # of Problems	7.9	(SD=3.6)		7.8	(SD=3.7)		8.3	(SD=4.)		8.1	(SD=4.0)	

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between the two models at baseline, using X^2 test of significance

[c] $p < .05$ between the two models at 6-month follow-up, using X^2 test of significance

[d] $p < .05$ between the treatment and control at 6-month follow-up, using X^2 test of significance

TABLE 7-16

LEVEL OF PATIENT SUPERVISION
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Level	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Model A												
Left alone over one hour [c]	1230	576	46.8	1178	594	50.4	1230	393	32.0	1178	421	35.7
Level of supervision [a]												
minimal supervision	1221	330	27.0	1175	341	29.0	1030	206	20.0	975	232	23.8
daytime supervision	1221	183	15.0	1175	195	16.6	1030	127	12.3	975	128	13.1
round-the-clock supervision	1221	708	58.0	1175	639	54.4	1030	697	67.7	975	615	63.1

Group & Level	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Model B												
Left alone over one hour	1395	658	47.2	1297	620	47.8	1395	472	33.8	1297	422	43.5
Level of supervision												
minimal supervision	1385	285	20.6	1294	293	22.6	1138	226	19.9	1044	233	23.9
daytime supervision	1385	282	20.4	1294	264	20.4	1138	160	14.1	1044	128	13.1
round-the-clock supervision	1385	818	59.1	1294	737	57.0	1138	752	66.1	1044	615	63.0

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[1] Percentages do not sum to 100 because categories are not mutually exclusive.

[a] $p < .05$ between the two models at baseline, using X^2 test of significance

[c] $p < .05$ between the two models at 6-month follow-up, using X^2 test of significance

TABLE 7-17

CAREGIVER RELATIONSHIP TO CLIENT TREATMENT & CONTROL GROUPS

Relationship	n	%
Spouse	2963	49.0
Daughter	1643	27.2
Daughter in Law	215	3.6
Son	487	8.1
Sister	138	2.3
Granddaughter	77	1.3
Female Friend	73	1.2
Sister in Law	17	0.3
Other Female	82	1.4
Brother	34	0.6
Grandson	21	0.4
Male Friend	20	0.3
Other Male	23	0.4
Brother in Law	2	0.0
Other	191	3.2
Self	13	0.2
Total	6040	100.0

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-18

CHANGES IN CAREGIVER WITHIN 6 MONTHS AFTER ENROLLMENT TREATMENT & CONTROL GROUPS, BY MODEL

Model and Treatment	n	%
Model A Treatment		
No Change	1311	93.8
Change	87	6.2
Model A Control		
No Change	1307	96.0
Change	54	4.0
Model B Treatment		
No Change	1499	94.3
Change	90	5.7
Model B Control		
No Change	1439	95.6
Change	66	4.4

SOURCE: UCSF/Instit. for Health & Aging. HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-19

CAREGIVER MARITAL STATUS
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Status	Treatment (N=1438)		Control (N=1392)	
	n	%	n	%
Model A				
Married	799	55.6	764	54.9
Widowed	548	38.2	516	37.1
Divorced	43	3.0	59	4.2
Separated	17	1.2	15	1.1
Never married	28	1.9	36	2.6
Other	1	0.1	1	0.1
Group & Status	(N=1641)		(N=1563)	
	n	%	n	%
Model B				
Married	940	57.2	898	57.4
Widowed	615	37.5	584	37.4
Divorced	57	3.5	45	2.9
Separated	6	0.4	5	.3
Never married	22	1.3	30	1.9
Other	1	0.1	1	0.1

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-20

CAREGIVER EDUCATION ATTAINMENT
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Education	Treatment (N=1412)		Control (N=1367)	
	n	%	n	%
Model A[a]				
No formal schooling	7	0.5	5	0.3
Elementary schooling	121	8.6	97	7.1
Some high school	202	14.3	190	13.8
High school or equivalent	404	28.7	411	30.1
Some college	344	24.4	362	26.5
College graduate	195	13.8	159	11.6
Post graduate	137	9.7	143	10.5
Group & Education	(N=1599)		(N=1534)	
	n	%	n	%
Model B				
No formal schooling	4	0.2	7	0.5
Elementary schooling	137	8.6	103	6.7
Some high school	207	13.0	191	12.5
High school or equivalent	510	31.9	480	31.3
Some college	381	23.9	369	24.1
College graduate	199	12.4	226	14.7
Post graduate	159	10.0	157	10.2

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between the two models at baseline, using X^2 test of significance

TABLE 7-21

HOURS PER WEEK CAREGIVER WORKS FOR PAY
TREATMENT & CONTROL GROUPS, BY MODEL

Group	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
	n	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD
Model A	445	35.8	14.0	454	34.8	15.4	357	36.9	14.0	355	35.7	15.7
% Not Working	763	71.1		707	70.1		785	72.9		751	72.0	
Group	Treatment			Control			Treatment			Control		
	n	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD
Model B	515	34.7	13.9	503	34.6	14.4	401	35.4	13.5	388	34.5	14.9
% Not Working	853	70.5		772	71.2		871	72.8		807	72.8	

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-22

CAREGIVER INCOME
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Income[1]	Treatment (N=1339)		Control (N=1293)	
	n	%	n	%
Model A				
$0-9,999	170	12.7	182	14.1
$10,000-14,999	220	16.4	222	17.2
$15,000-19,999	226	16.9	177	13.7
$20,000-24,999	177	13.2	166	12.8
$25,000-29,999	118	8.8	126	9.7
$30,000-34,999	94	7.0	99	7.7
$35,000-39,999	68	5.1	65	5.0
$40,000-44,999	62	4.6	66	5.1
$45,000-49,999	52	3.9	43	3.3
$50,000 and over	152	11.4	147	11.4
Group & Income[1]	(N=1536)		(N=1481)	
	n	%	n	%
Model B				
$0-9,999	203	13.2	212	14.3
$10,000-14,999	280	18.2	243	16.4
$15,000-19,999	253	16.5	227	15.3
$20,000-24,999	183	11.9	151	10.2
$25,000-29,999	136	8.9	143	9.7
$30,000-34,999	111	7.2	119	8.0
$35,000-39,999	78	5.1	74	5.0
$40,000-44,999	67	4.4	82	5.5
$45,000-49,999	59	3.8	52	3.5
$50,000 and over	166	10.8	178	12.1

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[1] When caregiver was a spouse and caregiver income was not separately reported, then the client's income was imputed as the caregiver's income for this table. Spouses accounted for 2898 of the 5649 cases reporting income.

[b] $p < .05$ between treatment and control groups at baseline, using X^2 test of significance

TABLE 7-23A

FAMILY REGULARLY CONTRIBUTES TO PATIENT CARE TREATMENT & CONTROL GROUPS, BY MODEL

	Baseline				6 Month			
	Treatment		Control		Treatment		Control	
Group & Contributes	(N=1408)		(N=1365)		(N=1139)		(N=1098)	
Model A	n	%	n	%	n	%	n	%
Yes, Spouse	722	51.2	673	49.4	502	44.1	492	44.8
Yes, Other than Spouse	243	17.3	230	16.8	169	14.9	164	14.9
No, Non-Spouse	443	31.5	462	33.8	468	41.1	442	40.3
Group & Contributes	(N=1593)		(N=1529)		(N=1268)		(N=1194)	
Model B	n	%	n	%	n	%	n	%
Yes, Spouse	898	56.3	872	57.0	644	50.8	622	52.1
Yes, Other than Spouse	229	14.4	209	13.7	240	18.9	205	17.2
No, Non-Spouse	466	29.3	448	29.3	384	30.3	367	30.7

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-23B

FAMILY (OTHER THAN SPOUSE) MONETARY CONTRIBUTIONS TOWARD PATIENT CARE TREATMENT & CONTROL GROUPS, BY MODEL

	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
Group	(N=243)			(N=230)			(N=169)			(N=164)		
	n	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD
Model A	182	$319.9	397.4	183	$288.8	677.5	138	$365.0	648.3	132	$235.4	310.8
Group	(N=229)			(N=209)			(N=240)			(N=205)		
	n	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD
Model B	199	$330.7	406.8	188	$370.0	451.1	172	$460.7	679.6	156	$541.0	1011.8

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-24

FUNCTIONAL IMPAIRMENT AMONG PRIMARY CAREGIVERS TREATMENT & CONTROL GROUPS, BY MODEL

Group & Measure	Baseline				6 Month			
	Treatment		Control		Treatment		Control	
Model A	n	% Yes	n	% Yes	n	% Yes	n	% Yes
Preparing meals	1415	16.1	1367	16.4	1137	7.0	1105	7.7
Doing housework	1415	24.6	1367	25.4	1140	19.0	1104	21.6
Doing Laundry	1414	13.0	1367	12.0	1139	9.2	1105	11.0
Doing Shopping	1414	14.3	1367	14.0	1137	9.8	1104	12.4
Taking medicine	1414	2.3	1367	1.8	1138	1.0	1105	1.4
Traveling	1415	14.3	1367	13.8	1139	6.4	1105	6.9
Money management	1414	2.3	1365	2.9	1139	1.1	1105	1.8
Telephoning	1414	2.2	1365	1.2	1139	1.7	1104	1.6
Eating	1414	4.7	1367	4.5	1140	2.0	1105	3.1
Getting out of bed/chair	1415	12.4	1367	13.2	1140	11.7	1103	11.0
Dressing	1415	4.3	1367	3.7	1140	4.1	1103	4.9
Bathing	1415	5.0	1367	3.6	1139	4.4	1103	4.8
Toileting	1415	1.3	1365	1.2	1138	1.1	1103	1.5
	Mean	S.D	Mean	S.D	Mean	S.D	Mean	S.D
	(n=1209)		(n=1157)		(n=1141)		(n=1103)	
Sum of IADL Limits	0.8	1.5	0.8	1.5	0.6	1.3	0.6	1.4
Sum of ADL Limits	0.3	0.7	0.3	0.6	0.2	0.7	.3	0.7
	n	% Yes	n	% Yes	n	% Yes	n	% Yes
Model B								
Preparing meals	1596	11.1	1529	12.1	1261	10.4	1187	10.5
Doing housework	1594	24.5	1531	25.1	1264	25.7	1188	25.3
Doing Laundry	1595	13.7	1530	14.0	1264	13.9	1187	13.1
Doing Shopping	1596	16.1	1531	16.4	1264	16.2	1186	15.6
Taking medicine	1596	1.8	1531	1.6	1264	1.0	1187	1.7
Traveling	1596	12.5	1530	12.8	1265	13.2	1187	15.4
Money management	1596	1.9	1531	2.2	1265	2.3	1187	1.9
Telephoning	1596	1.8	1530	2.1	1264	1.0	1187	2.1
Eating	1596	4.1	1531	4.2	1265	4.3	1187	3.6
Getting out of bed/chair	1595	11.3	1531	11.2	1265	12.6	1187	13.6
Dressing	1595	4.1	1531	4.0	1264	4.7	1187	3.7
Bathing	1596	4.0	1531	4.1	1264	4.9	1187	4.5
Toileting	1593	1.5	1530	1.6	1261	1.3	1186	1.6
	Mean	S.D	Mean	S.D	Mean	S.D	Mean	S.D
	(n=1360)		(n=1269)		(n=1265)		(n=1183)	
Sum of IADL Limits	0.8	1.6	0.8	1.6	0.8	1.5	0.9	1.6
Sum of ADL Limits	0.3	0.7	0.2	0.7	0.3	0.8	.3	0.7

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-25

CAREGIVER'S COMPARISON OF THEIR HEALTH TO HEALTH OF OTHERS TREATMENT & CONTROL GROUPS, BY MODEL

	Baseline				6 Month			
	Treatment		Control		Treatment		Control	
Group & Comparison	(N=1413)		(N=1366)		(N=1137)		(N=1102)	
	n	%	n	%	n	%	n	%
Model A								
Excellent	412	29.2	414	30.3	352	31.0	311	28.2
Good	687	48.6	641	46.9	496	43.6	510	46.3
Fair	266	18.8	258	18.9	229	20.4	223	20.2
Poor	48	3.4	53	3.9	60	5.3	58	5.3
Group & Comparison	(N=1591)		(N=1527)		(N=1263)		(N=1182)	
	n	%	n	%	n	%	n	%
Model B								
Excellent	468	29.4	432	28.3	334	26.4	327	27.7
Good	744	46.8	708	46.4	598	47.3	534	45.1
Fair	326	20.5	324	21.2	260	20.6	247	20.9
Poor	53	3.3	63	4.1	71	5.6	74	6.3

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-26

CAREGIVER AGE, HOURS OF CAREGIVING, STRESS & BURDEN, AND DEPRESSION TREATMENT & CONTROL GROUPS, BY MODEL

Group & Measures	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
Model A	Total	Mean	SD	Total	Mean	SD	Total	Mean	SD	Total	Mean	SD
Age	1426	73.6	19.6	1380	74.5	18.6	1224	74.7	18.4	1172	75.2	18.1
Primary cgvr hours	1425	88.7	57.2	1380	84.2	58.2	1128	57.5	49.9	1093	55.7	52.4
Second cgvr hours	1436	20.7	83.2	1391	18.2	61.0	1117	16.8	22.0	1078	16.9	22.9
Total cgvr hours	1437	108.6	96.6	1391	101.8	81.2	1134	73.7	54.4	1099	72.0	59.0
Stress & burden[1]	1416	15.2	9.3	1368	15.0	12.2	1139	14.7	20.1	1103	14.7	28.2
Depression[2]	1415	4.3	3.2	1366	4.2	3.2	1135	3.9	3.3	1095	4.2	3.5
Group & Measures	Treatment			Control			Treatment			Control		
Model B	Total	Mean	SD	Total	Mean	SD	Total	Mean	SD	Total	Mean	SD
Age	1635	74.3	19.5	1555	74.7	19.1	1384	74.6	19.4	1291	75.0	19.4
Primary cgvr hours	1619	93.5	59.6	1547	92.7	59.7	1249	64.5	54.3	1167	59.6	54.2
Second cgvr hours	1633	23.0	82.4	1558	21.2	75.1	1221	15.2	21.8	1150	15.1	20.5
Total cgvr hours	1635	115.6	96.4	1562	113.0	92.5	1267	78.2	60.1	1186	73.3	59.4
Stress & burden[1]	1600	15.6	9.8	1533	15.6	8.5	1266	15.9	27.9	1186	15.9	36.2
Depression[2]	1598	4.6	3.4	1531	4.6	3.3	1265	4.7	3.6	1183	4.7	3.6

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation , 1992

[a] $p < .05$ between models at baseline, using X^2 test of significance

[c] $p < .05$ between models at 6-month follow-up, using X^2 test of significance

[1] Low stress & burden: 0-8; Moderate stress & burden: 9-16; Severe stress & burden: 17 or more. Possible range: 0 - 36. Zarit, Reever & Bach-Peterson (1980).

[2] Scores greater than 5 reflect probable depression. Possible range: 0 - 15. Sheikl & Yesavage (1986).

TABLE 7-27A

CAREGIVER STRESS & BURDEN
MODEL A: TREATMENT & CONTROL GROUPS

Group & Measure	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
Model A	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Feels patient/family stress	1384			1336			1130			1095		
Never		212	15.3		167	12.5		165	14.6		157	14.3
Rarely		118	8.5		106	7.9		105	9.3		100	9.1
Sometimes		499	36.1		495	37.1		445	39.4		336	30.7
Quite frequently		344	24.9		331	24.38		245	21.7		268	24.5
Nearly Always		211	15.2		237	17.7		170	15.0		234	21.4
Feels patient/work stress	472			484			350			358		
Never		64	13.6		80	16.5		68	19.4		89	24.9
Rarely		48	10.2		59	12.2		41	11.7		45	12.6
Sometimes		186	39.4		178	36.8		143	40.9		104	29.1
Quite frequently		100	21.2		95	19.6		59	16.9		67	18.7
Nearly Always		74	15.7		72	14.9		39	11.1		53	14.8
Lacks time for self	1415			1368			1135			1105		
Never		280	19.8		258	18.9		280	24.7		280	25.3
Rarely		144	10.2		166	12.1		126	11.1		117	10.6
Sometimes		440	31.1		443	32.4		354	31.2		281	25.4
Quite frequently		300	21.2		268	19.6		197	17.4		194	17.6
Nearly Always		251	17.7		233	17.0		176	15.5		230	20.8
Feels angry around client	1412			1361			1137			1105		
Never		433	30.7		438	32.2		443	39.0		443	40.1
Rarely		272	19.3		271	19.9		182	16.0		153	13.8
Sometimes		573	40.6		531	39.0		397	34.9		374	33.8
Quite frequently		105	7.4		105	7.7		84	7.4		101	9.1
Nearly Always		29	2.1		16	1.2		30	2.6		32	2.9
Feels anxious with client	1413			1367			1138			1102		
Never		267	18.9		268	19.6		301	26.4		297	27.0
Rarely		161	11.4		149	10.9		99	8.7		91	8.3
Sometimes		599	42.4		571	41.8		495	43.5		424	38.5
Quite frequently		269	19.0		246	18.0		160	14.1		191	17.3
Nearly Always		117	8.3		133	9.7		82	7.2		96	8.7
Health has suffered	1412			1360			1137			1102		
Never		601	42.6		589	43.3		526	46.3		482	43.7
Rarely		144	10.2		113	8.3		123	10.8		94	8.5
Sometimes		397	28.1		349	25.7		276	24.3		266	24.1
Quite frequently		156	11.0		184	13.5		122	10.7		145	13.2
Nearly Always		114	8.1		125	9.2		86	7.6		112	10.2
Social life has suffered	1415			1365			1137			1105		
Never		336	23.7		309	22.6		312	27.4		287	26.0
Rarely		132	9.3		142	10.4		79	6.9		92	8.3
Sometimes		355	25.1		347	25.4		274	24.1		196	17.7
Quite frequently		276	19.5		267	19.6		193	17.0		193	17.5
Nearly Always		316	22.3		300	22.0		278	24.5		334	30.2
Feels loss of control	1413			1364			1137			1105		
Never		560	39.6		546	40.0		537	47.2		496	44.9
Rarely		154	10.9		146	10.7		110	9.7		90	8.1
Sometimes		370	26.2		315	23.1		250	22.0		224	20.3
Quite frequently		173	12.2		192	14.1		125	11.0		123	11.1
Nearly Always		156	11.0		165	12.1		113	9.9		167	15.1
Level of felt burden	1414			1366			1138			1105		
Not at all		184	13.0		184	13.5		181	15.9		170	15.4
A little		285	20.2		283	20.7		280	24.6		233	21.1
Moderately		417	29.5		377	27.6		320	28.1		275	24.9
Quite a bit		399	28.2		366	26.8		253	22.2		288	26.1
Extremely		129	9.1		156	11.4		102	9.0		136	12.3

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 27B

CAREGIVER STRESS & BURDEN
MODEL B: TREATMENT & CONTROL GROUPS

Group & Measure	Baseline						6 Month					
	Treatment			Control			Treatment			Control		
Model B	Total	n	%	Total	n	%	Total	n	%	Total	n	%
Feels patient/family stress	1340			1299			1261			1175		
Never		174	13.0		132	10.2		249	19.7		232	19.7
Rarely		98	7.3		107	8.2		104	8.2		91	7.7
Sometimes		477	35.6		480	37.0		379	30.1		360	30.6
Quite frequently		347	25.9		368	28.3		253	20.1		241	20.5
Nearly Always		244	18.2		212	16.3		276	21.9		251	21.4
Feels patient/work stress	566			569			412			399		
Never		99	17.5		115	20.2		73	17.7		77	19.3
Rarely		59	10.4		52	9.1		47	11.4		45	11.3
Sometimes		195	34.5		199	35.0		136	33.0		130	32.6
Quite frequently		126	22.3		131	23.0		76	18.4		69	17.3
Nearly Always		87	15.4		72	12.7		80	19.4		78	19.5
Lacks time for self	1598			1532			1267			1188		
Never		237	14.8		222	14.5		276	21.8		265	22.3
Rarely		161	10.1		172	11.2		119	9.4		106	8.9
Sometimes		522	32.7		493	32.2		349	27.5		290	24.4
Quite frequently		382	23.9		352	23.0		229	18.1		203	17.1
Nearly Always		296	18.5		293	19.1		290	22.9		317	26.7
Feels angry around client	1597			1529			1267			1186		
Never		432	27.1		419	27.4		441	34.8		437	36.8
Rarely		318	19.9		291	19.0		193	15.2		164	13.8
Sometimes		673	42.1		667	43.6		488	38.5		442	37.3
Quite frequently		142	8.9		123	8.0		91	7.2		86	7.3
Nearly Always		32	2.0		29	1.9		51	4.0		52	4.4
Feels anxious with client	1596			1530			1267			1186		
Never		228	14.3		239	15.4		254	20.0		257	21.7
Rarely		208	13.0		171	11.2		140	11.0		106	8.9
Sometimes		673	42.2		651	42.5		484	38.2		428	36.1
Quite frequently		328	20.6		318	20.8		172	13.6		187	15.8
Nearly Always		159	10.0		151	9.9		214	16.9		201	16.9
Health has suffered	1597			1528			1265			1187		
Never		550	34.4		526	34.4		460	36.4		450	37.9
Rarely		189	11.8		182	11.9		139	11.0		121	10.2
Sometimes		519	32.5		472	30.9		327	25.8		273	23.0
Quite frequently		216	13.5		213	13.9		167	13.2		160	13.5
Nearly Always		123	7.7		135	8.8		169	13.4		175	14.7
Social life has suffered	1598			1531			1266			1185		
Never		298	18.6		311	20.3		252	19.9		257	21.7
Rarely		163	10.2		140	9.1		99	7.8		79	6.7
Sometimes		444	27.8		407	26.6		284	22.4		252	21.3
Quite frequently		315	19.7		296	19.3		209	16.5		203	17.1
Nearly Always		378	23.7		377	24.6		418	33.0		389	32.8
Feels loss of control	1598			1531			1266			1186		
Never		572	35.8		543	35.5		494	39.0		443	37.4
Rarely		186	11.6		184	12.0		102	8.1		120	10.1
Sometimes		448	28.0		389	25.4		299	23.6		262	22.1
Quite frequently		192	12.0		213	13.9		134	10.6		136	11.5
Nearly Always		200	12.5		202	13.2		230	18.2		219	18.5
Level of felt burden	1595			1530			1267			1187		
Not at all		170	10.7		166	10.8		129	10.2		143	12.0
A little		311	19.5		305	19.9		245	19.3		229	19.3
Moderately		463	29.0		440	28.8		369	29.1		306	25.8
Quite a bit		438	27.5		420	27.5		317	25.0		287	24.2
Extremely		213	13.4		199	13.0		201	15.9		217	18.3

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-28

CAREGIVER DEPRESSION
MODEL A: TREATMENT & CONTROL GROUPS

Group & Measure	Baseline				6 Month			
	Treatment		Control		Treatment		Control	
	n	% Yes	n	% Yes	n	% Yes	n	% Yes
Model A								
Basically satisfied with life	1414	35.7	1367	35.9	1135	32.2	1104	39.0
Dropped many activities	1415	63.3	1367	59.8	1136	57.3	1103	58.3
Life feels empty	1415	28.8	1367	25.1	1133	25.2	1101	28.6
Often gets bored	1415	29.3	1367	28.8	1134	25.9	1103	27.1
Good spirits most of the time	1415	15.8	1366	14.1	1133	12.0	1103	15.0
Afraid bad event will happen	1415	23.9	1367	25.3	1135	25.3	1096	25.9
Feels happy most of the time	1415	26.9	1367	25.5	1133	24.4	1101	26.4
Often feels helpless	1415	42.8	1367	46.0	1135	39.9	1097	44.0
Prefers home over outings	1415	42.4	1366	39.1	1134	36.2	1102	32.8
More problems with memory	1415	18.0	1367	18.0	1134	15.1	1102	18.2
Wonderful to be alive	1414	9.9	1367	8.9	1133	9.2	1102	11.4
Feels worthless	1415	11.1	1364	12.0	1134	9.8	1099	12.2
Feels full of energy	1415	51.5	1366	49.1	1133	51.4	1101	54.1
Feels situation is hopeless	1414	21.1	1366	22.8	1135	18.8	1103	20.9
Most others are better off	1415	15.8	1366	15.5	1136	11.5	1102	14.3
Group & Measure	Treatment		Control		Treatment		Control	
	n	% Yes	n	% Yes	n	% Yes	n	% Yes
Model B								
Basically satisfied with life	1597	39.1	1532	38.3	1264	37.7	1185	39.8
Dropped many activities	1598	64.1	1532	63.3	1265	62.5	1186	61.9
Life feels empty	1598	27.2	1530	28.4	1265	30.7	1184	31.3
Often gets bored	1597	30.6	1531	29.6	1265	28.2	1186	29.1
Good spirits most of the time	1599	16.5	1531	19.0	1265	16.6	1186	15.8
Afraid bad event will happen	1598	25.6	1530	28.3	1264	31.2	1186	32.1
Feels happy most of the time	1597	30.2	1529	31.1	1265	31.0	1186	31.0
Often feels helpless	1599	50.2	1531	46.8	1264	47.9	1185	48.6
Prefers home over outings	1599	38.9	1530	38.9	1265	41.7	1185	40.2
More problems with memory	1599	16.1	1531	15.3	1265	22.6	1185	19.4
Wonderful to be alive	1595	12.9	1531	12.0	1262	12.7	1186	14.0
Feels worthless	1598	13.7	1530	13.0	1265	12.8	1186	13.2
Feels full of energy	1598	50.5	1529	51.2	1265	52.0	1186	51.8
Feels situation is hopeless	1599	25.2	1531	24.0	1265	27.5	1186	29.8
Most others are better off	1599	19.0	1532	20.6	1265	18.2	1186	20.6

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between models at baseline, using X^2 test of significance

[c] $p < .05$ between models at 6-month follow-up, using X^2 test of significance

[d] $p < .05$ between treatment and control groups at 6-month follow-up, using X^2 test of significance

[1] Percentages do not sum to 100 because categories are not mutually exclusive.

TABLE 7-29

EFFECTS OF CAREGIVING ON CAREGIVER EMPLOYMENT TREATMENT & CONTROL GROUPS, BY MODEL

Group & Effect	Baseline				6 Month			
	Treatment (N=1416)		Control (N=1368)		Treatment (N=1141)		Control (N=1103)	
	n	%	n	%	n	%	n	%
Model A								
Had to leave job	166	11.7	174	12.7	65	5.7	66	6.0
Had to turn down job	97	6.9	118	8.6	52	4.6	44	4.0
Had to refuse promotion	88	6.2	82	6.0	39	3.4	30	2.7
Unable to seek work	153	10.8	181	13.3	85	7.5	92	8.3
Had to work fewer hours	280	19.8	267	19.6	190	16.7	171	15.5
Had to retire early	91	6.4	91	6.7	21	1.8	14	1.3
Group & Effect	Treatment (N=1593)		Control (N=1527)		Treatment (N=1266)		Control (N=1193)	
	n.	%	n	%	n	%	n	%
Model B								
Had to leave job	262	16.5	253	16.6	92	7.3	75	6.3
Had to turn down job	197	12.4	174	11.4	100	7.9	87	7.3
Had to refuse promotion	165	10.4	126	8.3	81	6.4	61	5.1
Unable to seek work	242	15.2	245	16.1	159	12.6	140	11.8
Had to work fewer hours	386	24.2	376	24.7	270	21.4	211	17.7
Had to retire early	161	10.1	149	9.8	64	5.1	46	3.9

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] p < .05 between models at baseline, using X^2 test of significance

[c] p < .05 between models at 6-month follow-up, using X^2 test of significance

[d] p < .05 between treatment and control groups at 6-month follow-up, using X^2 test of significance

TABLE 7-30

CAREGIVER SUPPORT GROUP SERVICES TREATMENT & CONTROL GROUPS, BY MODEL

Group & Status	Treatment			Control		
Model A	N	n	%	N	n	%
Attends demonstration's caregiver support group	1199	381	31.8	1145	192	16.8
Currently needs caregiver support group	1161	410	35.3	1129	306	27.1
Group & Status						
Model B	N	n	%	N	n	%
Attends demonstration's caregiver support group	1335	459	34.4	1249	249	19.9
Currently needs caregiver support group	1310	530	40.5	1223	366	29.9

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between models at baseline, using X^2 test of significance

[b] $p < .05$ between treatment and control groups at 6-month follow-up, using X^2 test of significance

TABLE 7-31

EDUCATION & TRAINING TOPIC AREAS COVERED TREATMENT & CONTROL GROUPS, BY MODEL

Group & Topic Area[1]	Treatment			Control		
Model A	Total	n	%	Total	n	%
Information about Alzheimer's Disease	1195	204	17.1	1142	38	3.3
Ways to control aggression or anger	1194	119	10.0	1141	22	1.9
Financial/legal information	1194	148	12.4	1141	22	1.9
Caregiving techniques	1194	118	9.9	1141	25	2.2
Home modifications	1194	91	7.6	1140	14	1.2
Ways to obtain services	1194	116	9.7	1140	16	1.4
Other training	1194	53	4.4	1140	12	1.1

Group & Topic Area[1]	Treatment			Control		
Model B	Total	n	%	Total	n	%
Information about Alzheimer's Disease	1333	241	18.1	1246	88	7.1
Ways to control aggression or anger	1333	155	11.6	1244	48	3.9
Financial/legal information	1333	145	10.9	1243	41	3.3
Caregiving techniques	1334	124	9.3	1243	43	3.5
Home modifications	1330	75	5.6	1243	17	1.4
Ways to obtain services	1331	95	7.1	1244	33	2.7
Other training	1328	44	3.3	1242	23	1.9

SOURCE: UCSF/Instit. for Health & Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[a] $p < .05$ between models at baseline, using X^2 test of significance

[b] $p < .05$ between treatment and control groups at 6-month follow-up, using X^2 test of significance

[1] Percentages do not sum to 100 because categories are not mutually exclusive, and are relative to nonmissing responses.

TABLE 7-32

EDUCATION & TRAINING TOPIC AREAS NEEDED TREATMENT & CONTROL GROUPS, BY MODEL

Group & Topic Area[1]	Treatment			Control		
Model A	Total	n	%	Total	n	%
Information about Alzheimer's Disease	1194	141	11.8	1141	123	10.8
Ways to control aggression or anger	1193	92	7.7	1140	97	8.5
Financial/legal information	1193	86	7.2	1140	76	6.7
Caregiving techniques	1193	91	7.6	1140	71	6.2
Home modifications	1193	60	5.0	1140	47	4.1
Ways to obtain services	1192	97	8.1	1140	104	9.1
Other training	1190	64	5.4	1135	28	2.5

Group & Topic Area[1]	Treatment			Control		
Model B	Total	n	%	Total	n	%
Information about Alzheimer's Disease	1335	158	11.8	1247	138	11.1
Ways to control aggression or anger	1334	124	9.3	1247	95	7.6
Financial/legal information	1334	84	6.3	1246	67	5.4
Caregiving techniques	1334	80	6.0	1245	69	5.5
Home modifications	1334	39	2.9	1245	39	3.1
Ways to obtain services	1334	85	6.4	1246	93	7.5
Other training	1331	70	5.3	1243	65	5.2

SOURCE: UCSF/IHA, HCFA-AD Evaluation, 1992

[a] $p < .05$ between models at baseline, using X^2 test of significance

[b] $p < .05$ between treatment and control groups at 6-month follow-up, using X^2 test of significance

[1] Percentages do not sum to 100 because categories are not mutually exclusive

TABLE 7-33A

REASONS FOR NON-USE OF ADULT DAY CARE TREATMENT & CONTROL GROUPS, BY MODEL

Group & Measure	Model A						Model B					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
% Using Service	1221	305	25.0	1159	150	12.9	1374	572	41.6	1280	294	23.0
Client too ill or disabled	849	161	19.0	949	119	12.5	797	241	30.2	981	247	25.2
Service not needed	868	439	50.6	966	527	54.6	797	206	25.8	976	267	27.4
Service not available/ known to caregiver	844	85	10.1	949	123	13.0	793	41	5.2	973	96	9.9
Application process too difficult	837	1	0.1	939	5	0.5	794	5	0.6	975	8	0.8
Waiting list too long	837	2	0.2	938	3	0.3	794	1	0.1	974	9	0.9
Services unaffordable	845	39	4.6	959	94	9.8	794	22	2.8	975	72	7.4
Services affordable but undesirable	837	0	0.0	938	1	0.1	794	4	0.5	974	11	1.1
Patient/Caregiver did not like/could not adapt	851	205	24.1	953	180	18.9	799	346	43.3	976	377	38.6
Transportation problem	842	42	5.0	945	71	7.5	795	34	4.3	974	40	4.1
Service of poor quality	837	2	0.2	938	1	0.1	794	2	0.3	973	2	0.2
Other reason	845	39	4.6	944	34	3.6	794	17	2.1	972	38	3.9

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[1] Percentages do not sum to 100 because categories are not mutually exclusive.

TABLE 7-33B

SATISFACTION AMONG USERS OF ADULT DAY CARE
MODEL A: TREATMENT & CONTROL GROUPS

Group & Reason	Treatment			Control		
Model A	Total	n	% Yes	Total	n	% Yes
Staff knowledgable, needed little supervision	307			149		
Never		1	0.3		1	0.7
Sometimes		7	2.3		2	1.3
Usually		20	6.5		10	6.7
Always		279	90.9		136	91.3
Could communicate adequately with staff	309			149		
Never		1	0.3		2	1.3
Sometimes		4	1.3		3	2.0
Usually		22	7.1		6	4.0
Always		282	91.3		138	92.6
Services offered at convenient times	310			149		
Never		9	2.9		5	3.4
Sometimes		8	2.6		9	6.0
Usually		11	3.5		9	6.0
Always		282	91.0		126	84.6
Services available as many weeks as needed	309			150		
Never		15	4.9		6	4.0
Sometimes		5	1.6		3	2.0
Usually		7	2.3		10	6.7
Always		282	91.3		131	87.3
Services available as many hours as needed	309			150		
Never		22	7.1		19	12.7
Sometimes		12	3.9		8	5.3
Usually		15	4.9		16	10.7
Always		260	84.1		107	71.3
Overall satisfaction with services	307			150		
Very satisfied		228	74.3		129	86.0
Satisfied		63	20.5		15	10.0
Dissatisfied		11	3.6		4	2.7
Very dissatisfied		5	1.6		2	1.3

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-33C

SATISFACTION AMONG USERS OF ADULT DAY CARE
MODEL B: TREATMENT & CONTROL GROUPS

Group & Reason	Treatment			Control		
Model B	Total	n	% Yes	Total	n	% Yes
Staff knowledgeable, needed little supervision	570			288		
Never		4	0.7		0	0.0
Sometimes		11	1.9		8	2.8
Usually		61	10.7		38	13.2
Always		494	86.7		242	84.0
Could communicate adequately with staff	576			289		
Never		4	0.7		0	0.0
Sometimes		9	1.6		3	1.0
Usually		47	8.2		25	8.7
Always		516	89.6		261	90.3
Services offered at convenient times	575			293		
Never		4	0.7		2	0.7
Sometimes		16	2.8		11	3.8
Usually		48	8.3		24	8.2
Always		507	88.2		256	87.4
Services available as many weeks as needed	572			290		
Never		9	1.6		1	0.3
Sometimes		14	2.4		11	3.8
Usually		47	8.2		22	7.3
Always		502	87.8		256	88.3
Services available as many hours as needed	573			287		
Never		28	4.9		8	2.8
Sometimes		33	5.8		27	9.4
Usually		78	13.6		33	11.5
Always		434	75.7		219	76.3
Overall satisfaction with services	576			297		
Very satisfied		430	74.7		207	69.7
Satisfied		119	20.7		78	26.3
Dissatisfied		19	3.3		9	3.0
Very dissatisfied		8	1.4		3	1.0

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-34

REASONS FOR NON OUT-OF-HOME RESPITE USE
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Measure[1]	Model A						Model B					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
% Using Service	1222	42	3.4	1161	37	3.2	1385	51	3.7	1287	53	4.1
Client too ill or disabled	1084	33	3.0	1039	24	2.3	1316	45	3.4	1211	34	2.8
Service not needed	1165	931	79.9	1115	890	79.8	1316	910	69.1	1215	822	67.7
Service not available/ known to caregiver	1085	96	8.8	1040	79	7.6	1314	200	15.2	1212	210	17.3
Application process too difficult	1081	1	0.1	1040	1	0.1	1313	3	0.2	1210	5	0.4
Waiting list too long	1081	2	0.2	1039	3	0.3	1312	3	0.2	1210	4	0.3
Services unaffordable	1082	92	8.5	1039	97	9.3	1312	89	6.8	1213	101	8.3
Services affordable but undesirable	1080	2	0.2	1038	0	0.0	1312	3	0.2	1209	3	0.2
Patient/Caregiver did not like/could not adapt	1081	95	8.8	1041	84	8.1	1315	163	12.4	1212	149	12.3
Transportation problem	1080	2	0.2	1039	3	0.3	1312	6	0.5	1210	4	0.3
Service of poor quality	1080	3	0.3	1039	6	0.6	1312	3	0.2	1209	2	0.2
Other reason	1085	18	1.7	1042	18	1.7	1313	11	0.8	1208	12	1.0

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[1] Percentages do not sum to 100 because categories are not mutually exclusive.

TABLE 7-35A

REASONS FOR NON-USE OF PERSONAL CARE SERVICE TREATMENT & CONTROL GROUPS, BY MODEL

Group & Measure[1]	Model A						Model B					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
% Using Service	1221	470	38.5	1157	330	28.5	1374	601	43.7	1275	426	33.4
Client too ill or disabled	679	1	0.1	775	1	0.1	769	3	0.4	838	4	0.5
Service not needed	736	652	88.6	821	642	78.2	772	597	77.3	840	592	70.5
Service not available/ known to caregiver	684	13	1.9	777	49	6.3	769	58	7.5	837	104	12.4
Application process too difficult	679	0	0.0	775	0	0.0	769	0	0.0	837	7	0.8
Waiting list too long	679	0	0.0	775	2	0.3	769	1	0.1	736	4	0.5
Services unaffordable	683	49	7.2	782	104	13.3	769	35	4.6	868	105	12.5
Services affordable but undesirable	678	0	0.0	774	3	0.4	769	0	0.0	837	5	0.6
Patient/Caregiver did not like/could not adapt	683	64	9.4	776	73	9.4	769	103	13.4	836	75	9.0
Transportation problem	679	0	0.0	775	0	0.0	769	0	0.0	837	2	0.2
Service of poor quality	679	1	0.1	775	4	0.5	769	7	0.9	839	6	0.7
Other reason	687	15	2.2	778	14	1.8	768	35	4.6	839	38	4.5

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation ; 1992

TABLE 7-35B

SATISFACTION AMONG USERS OF PERSONAL CARE SERVICES
MODEL A: TREATMENT & CONTROL GROUPS

Group & Reason	Treatment			Control		
Model A	Total	n	% Yes	Total	n	% Yes
Could depend on staff to arrive on time	466			315		
Never		5	1.1		5	1.6
Sometimes		40	8.6		29	9.2
Usually		84	18.0		54	17.1
Always		337	72.3		227	72.1
Staff were polite and courteous	474			328		
Never		1	0.2		0	0.0
Sometimes		11	2.3		5	1.5
Usually		36	7.6		26	7.9
Always		426	89.9		297	90.5
Staff knowledgeable, needed little/no supervision	476			328		
Never		10	2.1		4	1.2
Sometimes		37	7.8		16	4.9
Usually		45	9.5		43	13.1
Always		384	80.7		265	80.8
Could communicate adequately with staff	475			327		
Never		50	1.1		0	0.0
Sometimes		12	2.5		7	2.1
Usually		41	8.6		30	9.2
Always		417	87.8		290	88.7
Services offered at convenient times	476			328		
Never		5	1.1		5	1.5
Sometimes		34	7.1		18	5.5
Usually		40	8.4		44	13.4
Always		397	83.4		261	79.6
Services available as many weeks as needed	473			327		
Never		26	5.5		15	4.6
Sometimes		20	4.2		7	2.1
Usually		34	7.2		28	87.6
Always		393	83.1		277	84.7
Services available as many hours as needed	473			328		
Never		46	9.7		33	10.1
Sometimes		30	6.3		21	6.4
Usually		45	9.5		42	12.8
Always		352	74.4		232	70.7
Overall satisfaction with services	473			328		
Very satisfied		296	62.3		227	68.8
Satisfied		137	28.8		85	25.8
Dissatisfied		29	6.1		11	3.3
Very dissatisfied		13	2.7		7	2.1

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-35C

SATISFACTION AMONG USERS OF PERSONAL CARE SERVICES
MODEL B: TREATMENT & CONTROL GROUPS

Group & Reason	Treatment			Control		
Model B	Total	n	% Yes	Total	n	% Yes
Could depend on staff to arrive on time	559			398		
Never		7	1.3		4	1.0
Sometimes		53	9.5		28	7.0
Usually		151	27.0		99	24.9
Always		348	62.3		267	67.1
Staff were polite and courteous	592			428		
Never		1	0.2		0	0.0
Sometimes		19	3.2		8	1.9
Usually		89	15.0		53	12.4
Always		483	81.6		367	85.7
Staff knowledgable, needed little/no supervision	593			427		
Never		9	1.5		1	0.2
Sometimes		68	11.5		30	7.0
Usually		112	18.9		73	17.1
Always		404	68.1		323	75.6
Could communicate adequately with staff	595			427		
Never		4	0.7		2	0.5
Sometimes		36	6.1		16	3.7
Usually		92	15.5		51	11.9
Always		463	77.8		358	83.8
Services offered at convenient times	578			418		
Never		4	0.7		1	0.2
Sometimes		32	5.5		30	7.2
Usually		96	16.6		67	16.0
Always		446	77.2		320	76.6
Services available as many weeks as needed	586			425		
Never		15	2.6		3	0.7
Sometimes		33	5.6		28	6.6
Usually		82	14.0		59	13.9
Always		456	77.8		335	78.8
Services available as many hours as needed	578			418		
Never		39	6.7		27	6.5
Sometimes		73	12.6		61	14.6
Usually		99	17.1		71	17.0
Always		367	63.5		259	62.0
Overall satisfaction with services	578			418		
Very satisfied		347	58.3		274	64.0
Satisfied		186	31.3		124	29.0
Dissatisfied		46	7.7		23	5.4
Very dissatisfied		16	2.7		7	1.6

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-36A

REASONS FOR NON-USE OF HOMEMAKER /CHORE SERVICES
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Measure[1]	Model A						Model B					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
% Using Service	1222	447	36.6	1154	305	26.4	1375	456	33.2	1280	339	26.5
Client too ill or disabled	698	1	0.1	786	0	0.0	905	3	0.3	927	2	0.2
Service not needed	757	631	83.4	834	638	76.5	912	647	70.9	928	620	66.8
Service not available/ known to caregiver	699	19	2.7	789	46	5.8	904	96	10.6	927	113	12.2
Application process too difficult	698	0	0.0	786	0	0.0	904	1	0.1	927	3	0.3
Waiting list too long	698	0	0.0	786	0	0.0	904	1	0.1	927	1	0.1
Services unaffordable	708	98	13.8	801	156	19.5	903	133	14.7	930	178	19.1
Services affordable but undesirable	699	2	0.3	786	7	0.9	903	6	0.7	926	7	0.8
Patient/Caregiver did not like/could not adapt	702	38	5.4	787	33	4.2	905	66	7.3	925	47	5.1
Transportation problem	698	1	0.1	786	0	0.0	904	0	0.0	925	2	0.2
Service of poor quality	698	3	0.4	786	3	0.4	904	4	0.4	925	3	0.3
Other reason	701	11	1.6	789	8	1.0	905	43	4.8	925	35	3.8

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[1] Multiple reasons for non-use are reported

TABLE 7-36B

SATISFACTION AMONG USERS OF HOMEMAKER/CHORE SERVICES MODEL A: TREATMENT & CONTROL GROUPS

Group & Reason	Treatment			Control		
Model A	Total	n	% Yes	Total	n	% Yes
Could depend on staff to arrive on time	444			290		
Never		7	1.6		3	1.0
Sometimes		45	10.1		11	3.8
Usually		64	14.4		51	17.6
Always		328	73.9		225	77.6
Staff were polite and courteous	448			303		
Never		1	0.2		0	0.0
Sometimes		10	2.2		4	1.3
Usually		31	6.9		25	8.3
Always		406	90.6		274	90.4
Staff knowledgeable, needed little/no supervision	447			303		
Never		9	2.0		5	1.7
Sometimes		50	11.2		17	5.6
Usually		51	11.4		38	12.5
Always		337	75.4		243	80.2
Could communicate adequately with staff	446			301		
Never		5	1.1		3	1.0
Sometimes		21	4.7		13	4.3
Usually		46	10.3		21	7.0
Always		374	83.9		264	87.7
Services offered at convenient times	449			305		
Never		4	0.9		6	2.0
Sometimes		26	5.8		10	3.3
Usually		35	7.8		27	8.9
Always		384	85.5		262	85.9
Services available as many weeks as needed	444			302		
Never		32	7.2		11	3.6
Sometimes		17	3.8		10	3.3
Usually		28	6.3		30	9.9
Always		367	82.7		251	83.1
Services available as many hours as needed	444			302		
Never		50	11.6		28	9.3
Sometimes		29	6.5		21	7.0
Usually		33	7.4		29	9.6
Always		332	74.8		224	74.2
Overall satisfaction with services	444			302		
Very satisfied		272	61.0		210	68.9
Satisfied		118	26.5		76	24.9
Dissatisfied		34	7.6		15	4.9
Very dissatisfied		22	4.9		4	1.3

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-36C

SATISFACTION AMONG USERS OF HOMEMAKER /CHORE SERVICES
MODEL B: TREATMENT & CONTROL GROUPS

Group & Reason	Treatment			Control		
Model B	Total	n	% Yes	Total	n	% Yes
Could depend on staff to arrive on time	432			311		
Never		5	1.2		0	0.0
Sometimes		31	7.2		13	4.2
Usually		101	23.4		51	16.4
Always		295	68.3		247	79.4
Staff were polite and courteous	454			333		
Never		1	0.2		0	0.0
Sometimes		7	1.5		6	1.8
Usually		50	11.0		23	6.9
Always		396	87.2		304	91.3
Staff knowledgeable, needed little/no supervision	452			335		
Never		11	2.4		1	0.3
Sometimes		35	7.7		19	5.7
Usually		69	15.3		47	14.0
Always		337	74.6		268	80.0
Could communicate adequately with staff	448			332		
Never		2	0.4		1	0.3
Sometimes		22	4.9		10	3.0
Usually		55	12.3		27	8.1
Always		369	82.4		294	88.6
Services offered at convenient times	449			332		
Never		5	1.1		0	0.0
Sometimes		18	4.0		11	3.3
Usually		52	11.6		39	11.7
Always		374	83.3		282	84.9
Services available as many weeks as needed	446			330		
Never		7	1.6		6	1.8
Sometimes		13	2.9		13	3.9
Usually		49	11.0		26	7.9
Always		377	84.5		285	86.4
Services available as many hours as needed	443			329		
Never		17	3.8		17	5.2
Sometimes		35	7.9		30	9.1
Usually		62	14.0		31	9.4
Always		329	74.3		251	76.3
Overall satisfaction with services	443			329		
Very satisfied		268	58.5		222	66.1
Satisfied		155	33.8		96	28.6
Dissatisfied		22	4.8		6	1.8
Very dissatisfied		13	2.8		12	3.6

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation , 1992

TABLE 7-37A

REASONS FOR NON-USE OF COMPANION SERVICES
TREATMENT & CONTROL GROUPS, BY MODEL

Group & Measure[1]	Model A						Model B					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
% Using Service	1221	486	39.8	1154	221	19.2	1378	379	27.5	1276	230	18.0
Client too ill or disabled	680	5	0.7	863	9	1.0	979	16	1.6	1031	19	1.8
Service not needed	720	578	80.3	908	644	70.9	986	654	66.3	1034	636	61.5
Service not available/ known to caregiver	683	58	8.5	976	104	11.9	981	158	16.1	1032	191	18.5
Application process too difficult	679	1	0.1	865	2	0.2	978	1	0.1	1030	8	0.8
Waiting list too long	679	0	0.0	863	0	0.0	978	1	0.1	1030	3	0.3
Services unaffordable	683	64	9.4	875	136	15.5	978	85	8.7	1032	132	12.8
Services affordable but undesirable	679	1	0.1	864	5	0.6	978	3	0.3	1031	5	0.5
Patient/Caregiver did not like/could not adapt	682	60	8.8	870	83	9.5	978	128	13.1	1033	117	11.3
Transportation problem	679	0	0.0	864	0	0.0	978	1	0.1	1031	2	0.2
Service of poor quality	679	0	0.0	864	4	0.5	978	3	0.3	1031	3	0.6
Other reason	684	19	2.8	869	23	2.6	978	32	3.3	1031	33	3.2

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[1] Multiple reasons for non-use are reported

TABLE 7-37B

SATISFACTION AMONG USERS OF COMPANION SERVICES
MODEL A: TREATMENT & CONTROL GROUPS

Group & Reason	Treatment			Control		
Model A	Total	n	% Yes	Total	n	% Yes
Could depend on staff to arrive on time	480			222		
Never		2	0.4		1	0.5
Sometimes		33	6.9		5	2.3
Usually		59	12.3		17	7.7
Always		386	80.4		199	89.6
Staff were polite and courteous	483			226		
Never		1	0.2		0	0.0
Sometimes		8	1.7		3	1.3
Usually		28	5.8		7	3.1
Always		446	92.3		216	95.6
Staff knowledgeable, needed little/no supervision	483			226		
Never		12	2.5		5	2.2
Sometimes		27	5.6		8	3.5
Usually		38	7.9		17	7.5
Always		406	84.1		196	86.7
Could communicate adequately with staff	483			226		
Never		3	0.6		1	0.4
Sometimes		15	3.1		3	1.3
Usually		34	7.0		13	5.8
Always		431	89.2		209	92.5
Services offered at convenient times	484			227		
Never		5	1.0		1	0.4
Sometimes		21	4.3		6	2.6
Usually		24	5.0		16	7.0
Always		434	89.7		204	89.9
Services available as many weeks as needed	478			224		
Never		30	6.3		15	6.7
Sometimes		24	5.0		11	4.9
Usually		33	6.9		16	7.1
Always		391	81.8		182	81.3
Services available as many hours as needed	480			224		
Never		40	8.3		22	9.8
Sometimes		33	6.9		15	6.37
Usually		44	9.2		16	7.1
Always		363	75.6		171	76.3
Overall satisfaction with services	480			224		
Very satisfied		328	67.9		168	73.7
Satisfied		105	21.7		48	21.1
Dissatisfied		33	6.8		8	3.5
Very dissatisfied		17	3.5		4	1.8

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-37C

SATISFACTION AMONG USERS OF COMPANION SERVICES
MODEL B: TREATMENT & CONTROL GROUPS

Group & Reason	Treatment			Control		
Model B	Total	n	% Yes	Total	n	% Yes
Could depend on staff to arrive on time	367			214		
Never		3	0.8		1	0.5
Sometimes		21	5.7		8	3.7
Usually		71	19.3		29	13.6
Always		272	74.1		176	82.2
Staff were polite and courteous	376			232		
Never		0	0.0		0	0.0
Sometimes		8	2.1		1	0.4
Usually		33	8.8		16	6.9
Always		335	89.1		215	92.7
Staff knowledgeable, needed little/no supervision	371			233		
Never		4	1.1		0	0.0
Sometimes		19	5.1		7	3.0
Usually		63	17.0		40	17.32
Always		285	76.8		186	79.8
Could communicate adequately with staff	377			231		
Never		4	1.1		1	0.4
Sometimes		13	3.4		4	1.7
Usually		43	11.4		15	6.5
Always		317	84.1		211	91.3
Services offered at convenient times	375			230		
Never		5	1.3		1	0.4
Sometimes		18	4.8		6	2.6
Usually		52	13.9		24	10.4
Always		300	80.0		199	86.5
Services available as many weeks as needed	364			222		
Never		17	4.7		4	1.8
Sometimes		18	4.9		14	6.3
Usually		47	12.9		27	12.2
Always		282	77.5		177	79.7
Services available as many hours as needed	370			223		
Never		27	7.3		9	4.0
Sometimes		37	10.0		29	13.0
Usually		64	17.3		39	17.5
Always		242	65.4		146	65.5
Overall satisfaction with services	370			223		
Very satisfied		258	67.7		157	66.8
Satisfied		93	24.4		66	28.1
Dissatisfied		22	5.8		9	3.8
Very dissatisfied		8	2.1		3	1.3

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

TABLE 7-38A

REASONS FOR NON-USE OF CASE MANAGEMENT SERVICES TREATMENT & CONTROL GROUPS, BY MODEL

Group & Measure[1]	Model A						Model B					
	Treatment			Control			Treatment			Control		
	Total	n	%	Total	n	%	Total	n	%	Total	n	%
% Using Service	1205	1154	95.8	1158	100	8.6	1362	1343	98.6	1285	162	12.6
Client too ill or disabled	51	1	2.0	975	0	0.0	19	0	0.0	1088	0	0.0
Service not needed	51	17	33.3	1039	363	34.9	18	9	50.0	1092	483	44.2
Service not available/ known to caregiver	51	7	13.7	982	692	70.5	19	3	15.8	1088	621	57.1
Application process too difficult	51	0	0.0	976	1	0.1	18	0	0.0	1089	3	0.3
Waiting list too long	51	0	0.0	976	0	0.0	18	0	0.0	1089	1	0.1
Services unaffordable	51	0	0.0	977	16	1.6	18	1	5.6	1089	29	2.7
Services affordable but undesirable	51	0	0.0	976	0	0.0	18	0	0.0	1088	3	0.3
Patient/Caregiver did not like/could not adapt	51	0	0.0	976	8	0.8	19	2	10.5	1087	11	1.0
Transportation problem	51	0	0.0	976	0	0.0	19	0	0.0	1088	1	0.1
Service of poor quality	51	0	0.0	976	2	0.2	19	0	0.0	1088	1	0.1
Other reason	54	27	50.0	978	6	0.6	19	3	15.8	1088	18	1.7

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

[1] Multiple reasons for non-use are reported

TABLE 7-38B

FREQUENCY OF CASE MANAGEMENT CONTACTS DURING PAST 6 MONTHS MODEL BY TREATMENT & CONTROL GROUPS

Method of Contact	Model A						Model B					
	Treatment			Control			Treatment			Control		
	n	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD
Phone	1191	4.0	3.2	86	2.8	3.4	1336	7.2	5.9	160	3.6	5.1
In-person	1208	1.7	1.4	85	2.6	4.2	1351	2.6	3.7	161	3.7	5.6
Caregiver initiated	1200	2.3	3.9	85	1.8	2.5	1330	1.8	5.0	156	2.8	4.2

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation , 1992

TABLE 7-38C

SATISFACTION WITH CASE MANAGEMENT SERVICES TREATMENT & CONTROL GROUPS, BY MODEL

Level of Satisfaction	Model A				Model B			
	Treatment		Control		Treatment		Control	
	n	% Yes	n	% Yes	n	% Yes	n	% Yes
Very Satisfied	747	65.0	55	62.5	988	73.8	91	58.0
Satisfied	347	30.2	27	30.7	286	21.4	58	36.9
Dissatisfied	48	4.2	2	2.3	55	4.1	6	3.8
Very Dissatisfied	7	0.6	4	4.5	10	0.7	2	1.3

SOURCE: UCSF/Instit. for Health and Aging, HCFA-Alzheimer's Disease Evaluation, 1992

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Appendix A
List of Eligible and Ineligible Disorders

Eligible Disorders

- Irreversible dementia, unspecified etiology
- Alzheimer's disease (with or without other dementing diseases)
- Vascular dementias including:
    - Multi-infarct dementia
    - Cortical microinfarcts
    - Lacunar dementia
    - Binswanger disease
    - Cerebral embolism by fat or air
- Dementia caused by degenerative diseases including:
    - Picks' disease,
    - Parkinson's disease
    - Huntington's disease
    - Progressive supranuclear palsy
    - Cerebellar degenerations
    - Amyotrophic lateral sclerosis (ALS)
    - Multiple sclerosis
    - Parkinson-ALS-dementia complex
    - Rare genetic and metabolic disease (Hallervorden-Spatz, Kuf, Wilson, late-onset metachromatic leukodystrophy, adrenoleukodystrophy)
- Dementia caused by specific infections including:
    - Creutzfeltd-Jakob disease (subacute spongiform encephalopathy)
    - Progressive multifocal leukoencephalopathy
    - Postencephalitic dementia
    - Behcet syndrome
- Dementia caused by trauma including:
    - Dementia pugilistica
    - Open or closed head injuries
- Irreversible dementia caused by Normal Pressure Hydrocephalus

Ineligible Disorders

Dementia caused by specific infections including:
- AIDS
- Herpes encephalitis
- Neurosyphillis (general paresis)
- Fungal meningitis or encephalitis
- Bacterial meningitis or encephalitis
- Parasitic meningitis
- Brain abscess

Reversible dementia caused by Normal Pressure Hydrocephalus

Dementia caused by space-occupying lesions including:
- Primary brain tumor
- Chronic or acute subdural hematoma
- Metastatic tumors (carcinoma, leukemia, lymphoma, sarcoma)

Dementia cause by autoimmune disorders including:
- Disseminated lupus erythematosus
- Vasculitis

Dementia caused by toxins including:
- Alcoholic dementia
- Metallic poisons (e.g., lead, mercury, arsenic, manganese)
- Organic poisons (e.g., solvents, some insecticides)

Dementia caused by psychiatric disorders including:
- Depression
- Sensory deprivation
- Other psychoses

Dementia caused by drugs including:
- Sedatives
- Hypnotics
- Antianxiety agents
- Antidepressants
- Antiarrhythmics
- Anticonvulsants
- Digitalis and Derivatives
- Drugs with anticholinergic effects
- Others (mechanism unknown)

Dementia caused by nutritional disorders including:

- Pellagra (vitamin B12 deficiency)
- Thiamine deficiency (Wernicke syndrome, acute phase treatable)
- Cobalamin (vitamin B12 deficiency)
- Folate deficiency
- Marchiafava-Bignami disease

Dementia caused by metabolic disorders including:

- Hyper and hypothyroidism (thyroid hormones)
- Hypercalcemia (calcium)
- Hyper and hyponatremia (sodium)
- Hypoglycemia (glucose)
- Hyperlipicemia (lipids)
- Hypercapnia (carbon dioxide)
- Cushing syndrome
- Addison's disease
- Remote effect of carcinoma

Appendix B
Minimum Case Management Assessment Areas

CLIENT/CAREGIVER ASSESSMENT

Demographic Information

Client

1. Emergency contact person for the client (i.e., name, address, telephone).
2. Client asset information.
3. Client Medicaid number (if applicable).

Caregiver

1. Caregiver asset information.
2. Caregiver Medicaid number (if applicable).

Health History Information

Client

1. Health problems.
2. Sleep patterns.
3. Pattern of falls.
4. Appetite information.
5. Medication information.
6. Alcohol/drug/cigarette use.
7. Sensory/communication information (e.g., hearing, vision, speech limitations).

Caregiver

1. Assessment of physical/health limitations.

Functional Information

1. Assessment of client's ability to drive.
2. Assessment of durable medical equipment (both condition of, and need for).

Psychiatric Information

1. Psychiatric symptoms checklist for the client.
2. Impression of caregiver's mental health status.

Home Environment Information

1. Assessment of home location (e.g., closest neighbor, busy streets).
2. Assessment of exterior hazards.
3. Assessment of interior hazards.
4. Case manager's overall assessment of client's living environment.

Social Support Information

1. Secondary caregiver data (for up to two secondary caregivers)
   a. Name
   b. Address
   c. Telephone number
   d. Relationship to client
   e. Availability to help
   f. Willingness to help
   g. Ability to help

2. Global home/living situation assessment
   a. Who lives with client.
   b. Reliability of support given client.
   c. Who makes decisions regarding the patient's care and who speaks for the patient.
   d. Case managers impressions regarding how the caregiver is currently coping.

Formal Service Utilization Information

1. Assessment of client's current service utilization including quantity and quality of current services (assessment of past service utilization is optional); including preferences for and or problems with service providers. Updates of services utilized since intake interview may be the primary focus of this assessment. Submit information on new service providers to BPA.
2. Assessment of caregiver's current service utilization including quantity and quality of current services.

Legal/Protective Information

Obtain and/or provide information on:
1. Powers of attorney.
2. Guardianship/conservatorship.
3. "Living wills" or other mechanisms that allow the client to refuse treatment.
4. Trusts.
5. Client's attorney (i.e., name, address, telephone number).
6. Case manager's impressions regarding potential for client/caregiver abuse and/or neglect.

MINIMUM COMPONENTS OF CARE/ACTION PLANS

1. Priority list of active client and/or caregiver problems.
2. Interventions and/or services to address priority problems.*
3. Provider(s) of service(s).
4. Objectives of the intervention/service.
5. Time frame for objectives to be met or to be reevaluated.
6. Client (if appropriate)/caregiver signature on care/action plan.
7. Development of mechanisms to monitor the status of secondary or pending problems and for updating the care plan when there are major changes in the status of client and/or caregiver.

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* Priority problems are defined as those problems that are assessed by the case manager as requiring an intervention that is feasible to be provided under the scope of the project in a timely fashion, as well as problems that if left unmanaged would result in serious health, safety or protective services consequences for the client.

TASKS SPECIFIC TO CASE MANAGEMENT FOR THE CLIENT WITH ALZHEIMER'S DISEASE

It is currently being debated in the literature whether clients who are cognitively impaired require different approaches to interventions and services than those who are not demented. It is the experience of the staff at the Institute for Health & Aging that while the basic tasks of the case manager in a community-based long-term care setting remain the same, there are some additional considerations that need to be taken into account when dealing with this specialized population. These include an increased focus on the role of the caregiver.

While up to one third of patients with Alzheimer's disease may in fact be living alone, it is generally possible to identify someone as the primary caregiver as is not always the case for other frail elderly. While the client should still be involved in the care plan goal setting process as much as possible, it is likely to be the caregiver who is the focus of much of case manager's time and attention.

Perhaps the most important function a case manager will perform with a caregiver is realistic goal setting and the development of an ongoing plan that does not rely on improvement on the client's part and/or the development of a miracle drug or cure in the near future. Two examples of this would be: (1) to set a goal to maintain certain of the client's functional abilities for as long as possible rather than to improve them; and (2) to control or minimize difficult behaviors rather than eliminate them completely.

Below we have listed several aspects of case management that require special attention when dealing with a demented client and his/her caregiver.

1. There may be additional time spent both helping the caregiver to anticipate the client's changing care needs at each stage of the disease and planning on how to meet changing care needs that take not only the client's needs but the caregiver's abilities into consideration. One example of this is the (often for male) caregiver's lack of experience in understand problems related to a client's lack of bowel and bladder control. They frequently feel they have been feeding the client something wrong and are totally unfamiliar with basic concepts such as bowel and bladder retraining and how to obtain and use incontinence supplies. As this stage appears to be approaching, intervention involving education, training and supplies from, for example, a nurse at a home health agency might stave off premature institutionalization.

2. There are so many deficits and problem behaviors that accompany the decline of the client with Alzheimer's disease, that the case manager needs to be aware and available to problem solve with the caregiver around each of these issues. These include: wandering and violent behavior, sexually inappropriate behaviors, and changes in the client's ability to eat ,walk, groom him/herself and go the bathroom alone. In addition, there may be mood changes (depression is common, especially in the early stages of Alzheimer's disease while later stages are often accompanied by paranoia), falling, burns and other accidents in the home as well as a variety of embarrassing and or socially inappropriate behaviors. The case manager should develop a handy reference

for tips, techniques and tools with which to equip the caregiver to deal with each of these problems, as well as the willingness to reinforce the caregiver's positive efforts to deal with them.

3. A major area of concern for caregivers will certainly be the client's cognitive decline. To some extent the loss of these abilities can be mitigated through the use of certain communication techniques that caregiver's can utilize to maintain maximum use of the client's cognitive abilities for as long as possible. Use of these techniques will at least minimize the likelihood of "catastrophic reactions" which can be very upsetting to the caregiver and can't be all that much fun for the client. The case manager should also be aware of the expected rate of cognitive decline in the client so that if a sudden drop occurs in the client's mental status, a medical work-up can be done in order to determine if there has been an adverse drug reaction or possibly a stroke.

4. The role of health care advocate for the client and caregiver is particularly necessary for the case manager who has an Alzheimer's disease client. Frequently the diagnosis will disqualify the client for any reimbursement benefits except under the category of custodial care so that the possibility of secondary (reimbursable) diagnoses and/or alternative care mechanisms need to be considered. In addition, care while the client is in an institutional setting is frequently unsatisfactory with either pharmaceutical or mechanical means employed as a way to control client behaviors rather than say, adequate staffing. Medicare and private insurance policies that supplement Medicare may well be a source of frustration to the caregiver. The case manager should know how to assist the caregiver in filling out these forms, especially if the case manager is concerned that cost of care is an issue. The case manager should also understand the procedure for appealing denied claims.

5. Many caregivers will wish at least to discuss with the case manager the possible ramifications of institutionalizing the client. The case manager therefore needs to be aware of skilled nursing facilities in the area and whether or not they accept Medicaid reimbursement or require spenddown guarantees. Most caregivers are unaware of the lack of Medicare reimbursement for skilled nursing facilities and the actual cost for a private pay bed as well as the occasionally appropriate alternative of residential care facilities, especially those licensed for non-ambulatory beds. The case manager also needs to have information on waiting lists and costs for "life care" and "levels of care" opportunities for spouses who do not wish to be physically separated from the client.

6. Because of the necessity for 24 hour care and supervision of the Alzheimer's disease client at the moderate to severe stages of the disease, "caregiver burden" may be more severe for many caregivers of clients with Alzheimer's disease. Caregivers may find it difficult to do "one more thing" and a more hands-on approach to information and referral may have to be taken. Certainly the

caregiver needs to do as much as possible for him/herself, but careful follow-up needs to be done following a referral to be certain that the caregiver acted upon the recommendation(s). More agency-originated referrals may occur than is usual with other client populations.

7. The case manager for clients with Alzheimer's disease also must be a quasi-legal and financial planning expert. Caregivers need to have explanations (as well as written material provided) of guardianship, conservatorship and trust options as well as powers of attorney, durable powers of attorney, and powers of attorney for health care as they are structured under the state laws in which the case manager practices. Sample power of attorney forms as well as right to die or living will materials should also be available from the case manager. If separation of asset options exist the caregivers should be made aware of these well in advance of need, as well as appropriate methods of spenddown. Again, the use of these methods of controlling the client's finances can often make the difference between the client's ability to be at home or in an institution.

8. While the social services maze is not quite as bad as the health care maze, it might be more humiliating. Social services are usually not as familiar to the client and his/her caregiver as medical care and so should be carefully explained to the caregiver. Share of cost procedures be a deterrent to the use of social services and the case manager may have to handle this him/herself with the client's permission. Eligibility criteria will also be conflicting and confusing. Some programs such as Older Americans Act programs have age but no income criteria while Title XX programs are just the opposite and SSI has both. The case manager must steer the client and caregiver through this maze.

9. From a clinical perspective, the case manager for someone with Alzheimer's disease should be aware of the appropriateness of psychiatric referrals and use of the public mental health system. In some states mental health conservatorships are the only legal way to control the financial affairs and personal care of a person with Alzheimer's disease. In other states geriatric mental health services cannot be provided to people with an organically-based mental disorder. A plan needs to be developed in case the client requires an involuntary short term institutional hold in order to evaluated or assessed. A relationship probably needs to be established with at least two psychiatrists in the community who are experienced and/or board certified geriatric psychiatrists for assistance in these situations.

10. Case managers need to be aware of the basic medications frequently used with Alzheimer's patients in order to communicate with physicians if problems with the medications begin to occur that may indicate over medication, side effects, interactions or toxicity. Communicating with the physician and other health professionals in an informed manner may well be the difference between appropriate and inappropriate care for the client. While the case

manager should never attempt to give medical advice, knowledge of the treatment techniques associated with Alzheimer's disease is an essential part of good case management. Either a Physician's Desk Reference (PDR) or the American Drug Index* should be available for this purpose.

11. Family support techniques of the case manager may also need be used in a different way than traditional case management. Case managers should be aware of the mental health literature regarding the "burden" and high incidence of clinical depression experienced by caregivers and the techniques that can be used to alleviate those problems. Referrals to mental health professionals for counseling and/or psychotropic medications such as mood elevators may also need to be coordinated as part of the care plan. For less severe problems, support groups for caregivers of people with Alzheimer's disease may be useful.

12. With case management for Alzheimer's disease clients an emergency plan or a "nights and weekends" contingency plan needs to be in place. If the caregiver experiences a crisis and the client cannot be left alone, the case manager may well be called on to handle the situation. If a respite worker fails to show up or at 2:00 AM that the client falls going to the bathroom, the case manager may be contacted. This plan needs to involve the use of emergency services as well as guidelines for delineating between emergency and non-emergency situations that might be able to be put off until morning.

Overall, the case management approach for clients with Alzheimer's disease may require a more directive approach with clients and family members because of the frequency with which basic health and safety issues may be involved . In addition, legal constraints may dictate what has to happen in a certain situation instead of professional nursing or social work standards. Traditional mental health professional principles such as the right of the client to self determination and confidentiality may also have to be examined in a new light. All of this requires a new look at conventional case management methods which this demonstration will help provide.

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* American Drug Index· N.F. Billups (ed) published by the Facts and Comparison Division, J.B. Lippincott company, 111 West Port Plaza, Suite 423, St. Louis Missouri 63146-3098.

Appendix C

Technical Assistance Meeting Agendas

MEDICARE ALZHEIMER'S DISEASE DEMONSTRATION

CASE MANAGEMENT TECHNICAL ASSISTANCE MEETING

MARRIOTT INNER HARBOR
110 SOUTH EUTAW STREET
BALTIMORE, MARYLAND

MARCH 26TH - 27TH, 1991

TUESDAY, MARCH 26TH

9:00 - 9:30 Welcome and Introductions

9:30 - 10:00 Additions/Revisions to Agenda
- a. Sharing of documentation

10:00 - 10:30 Reasons for underutilization of services by AD caregivers (excluding mental health)

Readings:

1) U. S. Congress, Office of Technology Assessment, 1990. "The limited use of services" and "Personal factors that may interfere with individuals ability or willingness to use services" from Chapter 3 of Confused Minds Burdened Families; Finding Help for People with Alzheimer's and Other Dementias. Washington D. C.: U. S. Government Printing Office, OTA-BA-403 108-122.

10:30 - 10:45 Break

10:45 - 12:30 Group Discussion regarding this issue addressing:

1) Gender differences in service utilization
2) Adult children v.s. spouses
3) Issues of quality in service delivery
4) Overcoming language and cultural barriers
5) Health care v.s. social services

12:30 - 2:00 Lunch

2:00 - 2:30 Introduction to approaches to mental health service delivery (including support groups)

Readings:

1) Sargent, S. Stansfield, 1990. "Introduction" from S. Sargent (ed) Non-Traditional Therapy and Counseling with the Aged. New York: Springer Publishing Co., 1-11.
2) Henderson J. N., 1990. "Alzheimer's disease in a cultural context" in J. Sokolovsky (ed.), The Cultural Context of Aging. New York: Bergin and Garvey, 315-330.
3) Gatz, M., Smyer, M., and Lawton, M. P., 1980. "The mental health system and the older adult," from L. W. Poon (ed.) Aging in the 1980's. Washington D. C: APA, 5-18.

2:30 - 3:30 Group discussion of this issue including:

1) The Memphis model
2) Accessing peer and lay counselors
3) Using community mental health resources and LCSW's
4) Increasing attendance at support groups
5) Finding cultural and age appropriate interventions

3:30 - 3:45 Break

3:45 - 5:00 Site specific issues around implementing the model:

1) Dealing with attrition through death or institutionalization (Portland)
2) Client eligibility in assisted living facilities (Portland)
3) The MMSE (Rochester)
4) Role of CM while client is institutionalized (Memphis)
5) Better ways to designate non-CM responsibilities (Rochester)
6) Broader perspective on program goals (Rochester)
7) "Capacity Building" (Minneapolis)

WEDNESDAY, MARCH 27TH

9:00 - 9:30 Introduction to the problem family and elder abuse issues

Readings:

1) Myers, J. E., 1987. "Family stress situations and helping responses " from J.E. Myers, Adult Children and Aging Parents, 115-150.
2) Steinmetz, S R., 1983. "Elder abuse" from Aging, Third Edition. Guilford, CT: The Dushkin Publishing Group, 222-225.

9:30 - 10:30 Group discussion of this issue including:

1) Causes of abuse
2) Family vs institutional abuse
3) Role of the demonstration case manager
4) Reporting requirements
5) Legal alternatives
6) Protecting the client: Is APS adequate?

10:30 - 10:45 Break

10:45 - 12:30 Issues around client institutionalization including role of CM in:

1) Avoiding it if possible
2) Easing the transition if it occurs

Readings:

1) Ferris, S. et al, 1987. "Institutionalization of Alzheimer's disease patients: Reducing precipitating factors through family counseling." Home Health Care Services Quarterly, 8 (1):23-50.
2) Schneewind, E. H. "The Reaction of the Family to the Institutionalization of an Elderly Member: Factors Influencing Adjustment and Suggestions for Easing the Transition to a New Life Phase." Journal of Gerontological Social Work, 15:121-136.

12:30 - 2:00 Lunch

2:00 - 3:30 Time Management Discussion - Dividing into 1 to 100 and 1 to 30 sites

3:30 - 3:45 Break

3:45 - 5:00 Feedback from sites to evaluation team

1) Demonstration "successes"
2) Ongoing problems
3) Suggestions

ANNUAL SITE DIRECTOR MEETING
AND
MODEL B CASE MANAGER TECHNICAL ASSISTANCE MEETING

JUNE 11 - 13, 1990

TREMONT PLAZA HOTEL BALTIMORE, MARYLAND

AGENDA ONE

ANNUAL SITE DIRECTOR MEETING
(FOR ALL SITES)

DAY ONE - JUNE 11, 1990

Introduction and Welcome (9:00 to 9:15 am)

Enrollment and Outreach (9:15 to 12:00 pm)

- o Overview of current enrollment and projections, include the status of duplications and rollovers, and expected attrition
- o Sites report on the strategies they have tried and where their referrals are coming from (10 minutes per site)
- o Discuss strategies that have been successful
- o Discuss possible new approaches, e.g.,mass mailings, paying physicians, telemarketing, expanding the catchment area.

Lunch (Noon to 1:30)

- o Extension of the enrollment period and reducing the disenrollment- phase out period and/or using staggered disenrollment: operational and political implications. (1:30 to 2:30 pm)
- o Implications for the demonstration and the evaluation design under varied enrollment estimates (2:30 to 4:00 pm)
  - – maintaining the "Client to Case Manager Ratios"
  - – reduced enrollment targets and effects on statistical power
  - – redistributing budgets: increasing funds to sites with expanded enrollment targets, reducing funds to sites with lowered targets
  - – "Steady State" enrollments and the use of comparison group cases to maintain case manager-to-client ratios.

Break (4:00 to 4:15 pm)

- Budgetary implications of the emergent alternatives (4:15 to 5:30 pm)
  - administrative
  - service funds
  - staffing

DAY TWO - JUNE 12, 1990

Reassessment Process (9:00 to 12:00 pm)

- Summarize the evaluation's client recontacting procedures and the changes made in the "Intake Questionnaire."
- Have sites discuss their reassessment process.
- Establish agreement on the minimum elements of this process and how the evaluation field work will coordinate with this activity. (Break the session into Model A and Model B work groups: 9:30 to 12:00.)

Lunch (12:00 to 1:30 pm)

HCFA Fiscal Procedures (1:30 to 3:30 pm)

- Issues or points of clarification from HCFAs point of view
- General questions from sites
- Discussion of the service classification codes being used by sites

Break (3:30 to 3:45 pm)

General Questions from the Site Directors (The agenda items are to be developed) (3:45 to 5:00 pm)

- Service delivery issues
- Questions regarding evaluation design procedures
- Technical assistance issues

AGENDA TWO

MODEL B CASE MANAGER TECHNICAL ASSISTANCE MEETING (FOR MODEL B SITES)

JUNE 13, 1990

Introduction and Welcome (9:00 to 9:30 am)

Objectives for the Meeting (9:30 to 10:00 am)

- Understanding basic components of case management for people with Alzheimer's disease
- Identify specific problems and concerns of the 1 to 30 model sites
- Share successful techniques for dealing with these issues across sites
- Other identified objectives

Input from the Sites (10:00 to 11:00 am)

A general overview from each site covering specific areas of concern, success stories and ongoing issues encountered so far in implementing the 1 to 30 model.

Discussion of Case Management (11:15 to 12:00 pm)

Discussion of three handouts on (1) the role of case management in community-based long-term care settings, (2) principle components of case management and (3) special issues involving case management for clients with Alzheimer's disease.

Lunch (Noon to 1:30 pm)

Issues Involving Service Providers (1:30 to 2:45 pm)

- Sharing experiences on ways of using leverage to obtain appropriate, timely and reasonably priced services for clients
- Resolving issues on the use of independent contractors
- Identifying and resolving barriers to service utilization by caregivers
- Training service providers

Break (2:45 to 3:00 pm)

Training and Supporting Caregivers (3:00 to 4:00 pm)

- Sharing training and education experiences and materials
- Establishing successful caregiver support groups

Miscellaneous Issues (4:00 to 4:30 pm)

- Use of consultants (especially around pharmacology issues)
- Documentation
- Defining rollovers
- Client-to-case manager ratios

Summary and Conclusions (4:30 to 5:00 pm)

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